Beyond Guardianship:

Toward Alternatives That Promote Greater Self-Determination

National Council on Disability

March 22, 2018

National Council on Disability (NCD)
1331 F Street NW, Suite 850
Washington, DC 20004

Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination

National Council on Disability, March 22, 2018
Celebrating 30 years as an independent federal agency

This report is also available in alternative formats. Please visit the National Council on Disability (NCD) website (www.ncd.gov) or contact NCD to request an alternative format using the following information:

ncd@ncd.gov Email

202-272-2004 Voice

202-272-2022 Fax

The views contained in this report do not necessarily represent those of the Administration, as this and all NCD documents are not subject to the A-19 Executive Branch review process.

National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

March 22, 2018

President Donald J. Trump
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit its report, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, which provides a comprehensive review of guardianship against the backdrop of the civil rights advancements of individuals with disabilities in the past several decades. While people with a variety of disabilities may face guardianship, the burgeoning aging population in America has forced issues surrounding guardianship to the fore in national media coverage and policy debates in recent years, making NCD's report a timely contribution to policy discussions.

Guardianship generally involves a state-court determination that an individual lacks the capacity to make decisions with respect to their health, safety, welfare, and/or property. Although guardianship is governed by state law, it entails the removal of rights protected by the U.S. Constitution. Additionally, individuals who are subject to guardianship are also protected by the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, which are laws intended to increase the ability of individuals to live and work in the community, encourage participation in civic life, and to promote self-determination for individuals with disabilities.

The *Beyond Guardianship* report explains how guardianship law has evolved, explores due process and other concerns with guardianships, offers an overview of alternatives to guardianship, and identifies areas for further study. The report includes a review of existing scholarship on the topic as well as the results of a qualitative study of individuals with experience in guardianship and its alternatives, and offers major findings and recommendations to Congress, the Administration, and to state and local government.

We stand ready to work with you and your Administration to work for improvements to the way in which individuals with disabilities who may require decision assistance are treated in the legal system and provided with assistance.

Respectfully,

Neil Romano
Chairman

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

National Council on Disability Members and Staff

Members

Clyde E. Terry, *Chairperson*
Benro T. Ogunyipe, *Vice Chairperson*
Billy W. Altom
Rabia Belt
James T. Brett
Bob Brown
Daniel M. Gade
Wendy S. Harbour
Neil Romano

Staff

Vacant, Executive Director
Joan M. Durocher, General Counsel & Director of Policy
Amy Nicholas, Attorney Advisor
Amged Soliman, Attorney Advisor
Ana Torres-Davis, Attorney Advisor
Anne Sommers, Director of Legislative Affairs & Outreach
Phoebe Ball, Legislative Affairs Specialist
Lisa Grubb, Director of Operations and Administration
Stacey S. Brown, Staff Assistant
Keith Woods, Financial Management Analyst

Acknowledgments

The National Council on Disability (NCD) wishes to express its appreciation to Quality Trust for Individuals with Disabilities who worked collaboratively with NCD to conduct the research and writing of this report. Additionally, we would like to thank the Institute on Disabilities at Temple University for its involvement in the qualitative study that is included in this report.

Contents

Glossary 11

Executive Summary 15

Summary of Methodology 17

List of Acronyms 25

Chapter 1: Guardianship Basics 27

Guardianship Fundamentals 27

Questioning the Assumptions of Guardianship 27

Rights at Risk in Guardianships 27

A Word on Language 30

Process of Obtaining Guardianship 30

Overview 30

Steps to Guardianship 31

Court Determination of Incapacity 34

Capacity and Scope of the Guardian's Authority 35

Ending a Guardianship 36

Chapter 2: Guardianship Against the Backdrop of Disability Rights Law 39

Guardianship as a Disability Policy Issue 41

History of Discrimination 42

The Eugenics Movement 42

Institutionalization 43

Civil Rights Expansion and Joining the Community 44

Deinstitutionalization 44

Independent Living 45

Rehabilitation Act 46

Developmental Disabilities Assistance and Bill of Rights Act 47

A Right to Public Education 47

Community Integration 48

The ADA Generation 50

CRPD—The ADA Goes Global 51

Chapter 3: Evolution of Guardianship Law 53
Ancient and British Roots 54
Pre-Reform: Guardianship in America 54
Late 1980s, Early 1990s: First Wave of Guardianship Reform 55
Early 2000s: Second Wave of Guardianship Reform 57
Present Day: Third Wave of Guardianship Reform 58
The Dawn of Supported Decision Making 60
Revising the UGPPA 61
Chapter 4: The Current Guardianship System in America 65
The Current System Lacks Data 65
Data on the Number of People Subject to Guardianship 65
Data on the Number of Filings 66
What Is Known from Limited Data 67
2014 SSA Representative Payee Report 67
2010 Study of the National Center for State Courts' Center for Elders and the Courts 68
State Data 69
What the Lack of Data Means 70
Does Guardianship Prevent Abuse or Lead to It? 70
Chapter 5: Capacity and the Role of "Experts" in Guardianship Proceedings 73
Introduction 73
Moving Away from the "Reasonable Man" Standard of Capacity 74
Philosophical Origins 74
Behavioral Economics 76
Capacity Determinations 76
Who Decides Capacity? 76
"Expert" Evidence 77
Who Are the Experts? 79
Varies by State 79
Shortcoming of Physicians as "Experts" 79
Tools the Experts Use 80
Tests and Questionnaires 80
ABA/APA Framework for Evaluations 81

Court Discretion and Due Process 82
Limited Guardianship and the Functional Model of Capacity 82
Chapter 6: Concerns About When and How Guardians Are Appointed 85
Due Process Concerns 85
Difficulty Accessing Zealous Representation 88
Overuse of Plenary Guardianship 88
Unequal Treatment Under the Law for People with ID/DD 89
School-to-Guardianship Pipeline for Youth with ID/DD 92
The Pipeline Problem 92
Alternatives to the Pipeline 94
Financial Costs of Guardianship 95
Cost of Justice 96
Public Funding of Guardianship 98
Professional Guardianship in the Absence of Sufficient Public Funding 99
Chapter 7: Concerns Once Guardianships Are in Place 101
Overview of Concerns 101
Guardianship: A Double-Edged Sword? 101
The Impact on Life Outcomes 102
Financial Abuse by Guardians 103
Overbroad Guardianship 104
Implications for Voting 105
Sexuality and Guardianship 106
Jurisdictional Issues 109
Restoration of Rights 110
ABA Commission on Law and Aging/Virginia Tech Center for Gerontology Study 111
Restrictions on Restoration Efforts 116
Chapter 8: Less-Restrictive Alternatives to Guardianship 119
Olmstead Necessitates Finding Alternatives to Guardianship 119
Introduction to Alternatives 119
A Practical Tool for Considering Alternatives 121
Alternatives by Context 122

Financial Decisions 122
Health Care Decisions 126
Educational Decisions 128
International Best Practices 129
The Trend Toward the Alternative of Supported Decision Making 130
Definition of Supported Decision Making 130
Benefits of Supported Decision Making 131
Areas for Greater Study with SDM Models 132
How Supported Decision Making Works 133
International and U.S. Support and Advancement of SDM 134
Next Steps for Supported Decision Making as an Alternative to Guardianship 137
Chapter 9: Stakeholder Experiences with the Guardianship System 139
Overview of NCD's Qualitative Study 139
Methodology 139
Analysis and Salient Themes 141
Treatment Within the Legal System 141
Supported Decision Making 146
Access to Information About the Guardianship Process and Possible Alternatives 149
Impact of Guardianship 152
National Disability Policy Goals and Initiatives 156
Chapter 10: Findings and Recommendations 161
Appendix A: Table of Authorities—State Guardianship Statutes 169
Appendix B: Developmental Disability Specific Guardianship Statutes 171
Appendix C: Contact Information for WINGS Groups* 173
Appendix D: Attorney Representation in Initial Guardianship Cases 175
Endnotes 179

Glossary

Adjudication: The process of a judicial determination; an adult under guardianship has generally been "adjudicated" to lack capacity.

Adult: An individual who is at least 18 years of age, regardless of disability.

Advance Directive: A witnessed document or documents that a person can use to provide instructions regarding their desires and preferences about medical treatment in the event that they become incapacitated. Such medical treatment may include, for example, life prolonging treatment or psychiatric treatment during a crisis. Often, an Advance Directive will include a power of attorney and a health care surrogate designation.

Agent: A person with the legal authority to act on behalf of another.

Alleged Incapacitated Person (AIP): A person who is the subject of a petition to determine capacity or guardianship, but who has not yet been adjudicated incapacitated.

Annual Accounting: A report states may require a guardian of the property to file itemizing expenditures and receipts made on behalf of the person subject to guardianship in the previous year. Some states allow the court to waive this requirement, particularly if the only income the person has is Social Security and the guardian is also the representative payee of such funds.

Annual Guardianship Plan: A report, filed by the guardian of the person, that some states require to be submitted to the court each year specifying the medical, mental, and physical care of the person subject to guardianship for the upcoming year.

Attorney ad Litem: An attorney who is appointed by the court to act as a legal advocate in the best interest of a child or incapacitated adult. Unlike attorneys in a normal attorney-client relationship, they do not necessarily advocate for the desired outcome of the individual they represent, but may advocate for an outcome the attorney deems in the person's best interest.

Best Interest: A type of decision making standard that may be used when making a decision on behalf of another person, particularly in court cases involving child custody or welfare. Compared to substituted judgment, it is seen as a more objective standard; emphasis is on the person's safety and wellbeing.

Capacity: An individual's ability to perform a specific task, such as to sign a contract; also refers to the legal ability to perform an act and to subsequently be bound by the act. May also be referred to as *competency*.

Clerk of the Court: Court officer responsible for filing papers, administration of cases, and keeping records of court proceedings. In some courts, the Clerk of the Court may play a role in reviewing accountings and reports filed by guardians.

Conflict of Interest: Situations in which an individual may receive financial or material gain or advantage from a decision made on behalf of another person, with whom they have a relationship.

Court Visitor or Monitor: Individual appointed to advise the court regarding whether an individual needs a guardian (and, if so, who it should be) or to report to the court whether an existing guardianship continues to be appropriate or necessary, what the condition of the individual subject to guardianship is, or whether the decisions being made on behalf of that individual are appropriate.

Durable Power of Attorney: A durable power of attorney is effective even after the principal becomes incapacitated. The attorney-in-fact can continue to act within the scope of authority granted under this power of attorney.

Family Guardian: A nonprofessional guardian who serves as guardian for an individual who is subject to guardianship. Although *family guardians* usually are related to the individual subject to guardianship, they may instead be friends or even volunteers. Although they can be reimbursed out of the estate, they are not serving as guardians in order to make a living. The definition of *family guardian* may vary from state to state.

Guardian: A person, institution, or agency appointed by a court to manage the affairs of another individual. The guardian may have the authority to manage personal and/or financial matters. Each state has specific laws that govern guardianship proceedings and the guardian's activities. States have separate laws and procedures for guardianship for minors and for adults with disabilities. States may use different terms to refer to guardians, such as *conservators*.

Guardian ad Litem: A person appointed to advise the court regarding the needs and best interests of a child or individual who either lacks capacity or, in some states, has been alleged to lack capacity.

Guardianship of the Person: A guardianship where the guardian is granted the authority by the court to make personal decisions for an individual. This means that the right to make personal decisions has been removed from the individual and transferred to a guardian. These rights may include, for example, the right to decide where to live, with whom to associate, and what medical treatment to receive or not receive.

Guardianship of the Property: A guardianship where the guardian is granted the authority by the court to manage and make decisions about another person's financial matters, benefits, real estate, and other property. This means that the right to make property decisions has been removed from the individual and transferred to the guardian. This is sometimes referred to as a *conservatorship* or *guardianship of the estate*.

Health Care Surrogate: An agent who has been given the authority to make health care decisions for a person either by the person through a durable power of attorney for health care or by operation of law.

Indigent: An individual with little to no resources and who may be entitled to an attorney paid for by the state, the appointment of a public guardian, and/or the waiver of court costs and fees.

Informed Consent: Consent, usually to a medical procedure or legal representation, given by a person after information disclosing the risks, benefits, and costs of undertaking a given action are divulged, so the person may make a free and uncoerced decision.

Limited Guardianship: A guardianship where the guardian only has the authority specifically given by court order. The person subject to a limited guardianship retains all other decision making rights not specifically outlined by the court order.

Magistrate Judge: A state official who makes decisions in legal cases just like a judge, but does not have as much power as a judge. Magistrates generally handle minor cases and, in some jurisdictions, may handle guardianships cases, especially those that are uncontested.

Plenary Guardianship: A guardianship where the court gives the guardian the power to exercise all legal rights and duties on behalf of the person subject to guardianship. The guardianship is of both the person and the property, and the individual subject to guardianship has been adjudicated completely incapacitated. This is the most restrictive form of guardianship.

Power of Attorney: A legal instrument, executed under state law, by which one person (called the *principal*) voluntarily appoints someone else (called the *attorney-in-fact* or *agent*) to legally act on their behalf with respect to certain decisions and under certain circumstances. A *durable power of attorney* is operative even after the individual has lost capacity. A *power of attorney for health care* is generally operative when the person becomes incapacitated.

Professional Guardian: A professional guardian is generally a private individual or organization who serves as guardian for numerous individuals subject to guardianship and is not a member of those individuals' families. Professional guardianship charge fees for carrying out their duties. They are generally paid out of the resources of the person subject to guardianship, when that person has such resources.

Public Guardian: A guardian who generally is either employed or funded by the state to provide guardianship services to individuals who have been determined incapacitated. Often, public guardians serve people who are indigent and/or are the responsibility of a state agency or entity.

Representative Payee: An individual, agency, or organization appointed by the Social Security Administration (SSA) to receive, manage, and spend Social Security benefits on behalf of and for the benefit of an individual who is entitled to the benefits but who has been determined by SSA to be unable to manage the resource.

Respondent: A person who is responding to a lawsuit or legal action. In guardianship, the alleged incapacitated person who is the subject of a petition for guardianship is the *respondent*.

Special Needs Trust: A type of trust that is established for the benefit of a person with disabilities. The assets in this type of trust are intended to supplement and protect public benefits, specifically Medicaid. The advantage of this type of trust is that its assets do not negatively impact the beneficiary's eligibility for Medicaid or other government programs as long as the trust is administered properly.

Standard of Proof: Refers to the duty or burden carried by the party responsible for proving the case. There are generally three standards of proof that can apply in legal cases: "beyond a reasonable doubt" (highest standard, applies in criminal cases and in guardianship cases in New Hampshire.), "clear and convincing" (second highest standard, which applies in most states' guardianship cases), and "preponderance of the evidence" (lowest standard, which applies in some states' guardianship cases and also may be the burden of proof in restoration cases).

Substituted Judgment: A standard of decision-making that should generally be used when making decisions on behalf of an adult with a disability, according to the National Guardianship Association. It refers to making a decision on behalf of an individual that is aligned with the decision they would have made for themselves if they had the capacity to do so. This includes understanding and considering the values and preferences of the individual for whom decisions are being made either as currently expressed or as expressed prior to the determination that the individual was incapacitated.

Trust: A fiduciary arrangement where the trustee manages money or property for the benefit of a beneficiary or beneficiaries. A trust is a separate legal entity that owns assets that are managed by the trustee for the benefit of the beneficiary or beneficiaries in accordance with the rules established by the trust. There are many different kinds of trusts, each of which provides different benefits.

Executive Summary

This report by the National Council on Disability (NCD) seeks to explain, evaluate, and contextualize a system that impacts a large number of people with disabilities, particularly intellectual, cognitive, and age-related disabilities. Although it has been an important part of Western law since the ancient Greeks, guardianship has not garnered the attention of policymakers and disability rights advocates the way other issues have. In fact, although NCD has consistently supported and encouraged the adoption of policies that promote the self-determination of people with disabilities, as well as the adoption of the Convention on the Rights of Persons with Disabilities and its Article 12 imperative "that all people with disabilities retain their legal capacity, even those who may need significant and intensive support to effectuate it,"[1] the Council has not, until now, explored how guardianship impacts people with disabilities or made recommendations regarding how to transform the way in which we assist people with disabilities who may need help managing money or property or making decisions that impact their health and welfare. Guardianship is a creature of state law, with a federal footprint that has historically been fairly small. However, guardianship has a profound impact on the people subject to it, as well as on their families and communities. The existence of a process through which an adult can essentially be found legally incapable of making decisions for themselves and another adult appointed to make decisions on behalf of that individual raises fundamental civil rights issues that are deserving of thorough examination. Additionally, the increase in the number of older Americans as the baby-boom generation enters retirement and growing concern over elder abuse has increased the level of interest in this topic among federal policymakers.

A foundational principal in our democracy is the legal presumption that once an individual reaches the "age of majority" and becomes an adult, he or she is capable of making decisions and taking certain legal actions is a foundational principle in our democracy.[2] Once a person turns 18, he or she can vote; sign contracts; make a will; and choose where to live, go to school, and work. Eighteen is not a magic number; people who are younger than 18 may make very rational decisions and individuals who are over that age often make poor decisions. However, mistakes are part of how we learn to make future decisions. As one of the guardianship professionals interviewed for the report explained, "We have to acknowledge that everyone . . . makes bad decisions, so we frequently have to acknowledge and respect the right for the person to make a 'wrong' decision."

The presumption of one's right to liberty, self-determination, and personal autonomy is fundamental to American culture, democracy and economy. In the first chapter of his 1869 book, *On Liberty*, English philosopher John Stuart Mill writes:

> The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign.[3]

In theory, people with disabilities are entitled to the presumption of capacity along with their peers without disabilities. However, throughout history, as law professor and recognized guardianship expert Robert Dinerstein notes:

> Society assumes that adults of typical intelligence, psychosocial functioning, and sensory ability are able to engage in all aspects of life—deciding where to live, whom (or whether) to marry, how to spend one's money (or to whom to leave it), for whom to vote—on an autonomous basis. . . . But for adults with disabilities, the picture has been and continues to be quite different. States have assumed that the mere status of having an intellectual or psychosocial disability (or some sensory disabilities) provides a sufficient basis to presume that the individual is unable to participate fully and autonomously in society, in other words, that the individual lacks the legal capacity to exercise his or her rights.[4]

Indeed, Mill offers this caveat: "those who are still in a state to require being taken care of by others must be protected against their own actions as well as against external injury." It is worth noting that he also denies that personal autonomy applies to ". . . those backward states of society in which the race itself may be considered as in its nonage." So, while Mill firmly establishes personal autonomy as the foundation of liberty, his words also serve as a reminder that the history of America is one of gradually expanding these fundamental principles to include people who were not, at its inception, assumed to possess the full complement of inalienable rights.

As we will explore throughout this report, Mills' and others' understanding of the implications of being dependent on others for personal care is antithetical to the Americans with Disabilities Act (ADA). However, Lawrence A. Frolik—another thoughtful scholar on guardianship whose thoughts will appear throughout this report—has argued that "[i]t is possible that the reform goals of personal autonomy and dignity are so at odds with reality so as to be unattainable."[5] That is a fair point to be considered if we are going to understand guardianship and propose reforms that are not only philosophically consistent with disability rights, but also serve as practical solutions for people with disabilities and their families. As one person interviewed for this report put it, ". . . if the Council were to connect the idea of autonomy with dignity, I think that would be such a powerful statement."

Indeed, throughout this report, NCD will explore the connections among autonomy, dignity, independence, and protection, and provide the reader with a better understanding

of guardianship, which directly impacts the lives of an estimated 1.3 million Americans with disabilities. It has often been noted that an individual subject to guardianship moves through the world indistinguishable from the rest of the population, except that he or she has undergone "a kind of civil death" and is "no longer permitted to participate in society without mediation through the actions of another if at all."[6] As one person with disabilities interviewed for this report explained, "I would feel kind of like a prisoner, knowing that all my decisions were up to someone else." On the other hand, there are those who view guardianship not as a restriction of rights, but as a form of protection and assistance. One guardian who was interviewed emphasized that guardianship "is in the best interest of the individual, and it's not a means or stripping rights or controlling." An attorney at a public guardian agency added that, without a finding of incapacity to contract, "what happens if that person signs a contract [but] . . . read[s at a] second grade level? [Now] they bought a car or . . . sold their house."

Throughout this report, NCD seeks to balance and recognize both of these viewpoints while remaining unwavering in the belief that "people who are [seniors] and people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence."[7] This is as true of individuals who need help making decisions as it is when they need housing, medical care, assistance with personal care, or any other kind of support. Guardianship must be measured not only by how well it protects individuals, but also by how well it advances their dignity, autonomy, and self-determination, and NCD seeks to explore both measurements throughout this report.

Summary of Methodology

This report provides an overview of the current state of guardianship law and practice and an overview of policy reforms and analysis of how effective or ineffective these efforts have been. In preparation for this report in October 2016, an extensive literature review was conducted of the relevant scholarship available in English with a preference for studies concluded within the past decade. The resources identified in that review form the backbone of the report. Additionally, in order to better understand the experiences with guardianship and decision making alternatives of people with disabilities, their families, and other stakeholders, qualitative interviews were conducted with 46 individuals with a range of experiences with guardianship. Although this is an insufficient number from which to glean statistically significant information, their responses helped guide the direction of this report. We report on the qualitative interviews in Chapter 9, and references to the interviews appear throughout the report. Additionally, the qualitative data is collected in a "white paper" that will appear on NCD's website as a companion to this report along with the literature review previously referenced.

This report is organized into 10 chapters. Chapter 1 will explain what "guardianship" is, where it comes from in terms of history and jurisprudence, and how it is used in modern times. Chapter 2 will trace the history of disability discrimination in the United States and describe the growth of the disability rights movement and how we think about what it means to be a person with a disability. Chapter 3 will provide background on past and current guardianship

reforms, including the motivation behind them. Chapter 4 will provide a snapshot of the current state of guardianship in the United States. Chapter 5 will examine the key concept of *capacity* and how experts and courts evaluate whether or not an individual is capable of making decisions for themselves. Chapter 6 continues the discussion of due process rights for individuals facing guardianship and the ongoing rights of individuals who are subject to guardianship, as well as an examination of some of the financial costs associated with guardianship. Chapter 7 examines specific issues that often arise in guardianship such as financial abuse and exploitation, health care decision making, and other areas that can be problematic and deserve close examination. Chapter 8 examines alternatives to guardianship and suggests ways that they can be made stronger and more viable sources of support for people with disabilities who need or want decision making assistance. Chapter 9 reports the findings from the study conducted for this report and brings forward the voices of people who have knowledge and experience that can enhance our understanding of guardianship and alternatives. Finally, Chapter 10 offers the findings and recommendations of the Council in the area of guardianship in light of the information presented in this report.

Findings and Recommendations

Finding 1: There is a lack of data on existing guardianships and newly filed guardianships.

Most states do not track on a statewide basis how many individuals are subject to guardianship, much less describe those guardianships in terms of basic demographic information, whether the guardian is a professional or family guardian, the extent of the guardian's authority, the assets involved, and other basic questions that would help policymakers and stakeholders make determinations about what reforms may be needed in guardianships or where resources should be directed to improve guardianship outcomes for people with disabilities.

Recommendations:

NCD recommends that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship. There are two ways production of this data should be approached:

- Federal agencies such as the Social Security Administration (SSA), the Centers for Medicare and Medicaid Services (CMS), the U.S. Department of Veterans Affairs (VA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and other relevant agencies should collect data on whether or not individuals they serve are subject to guardianship.

Findings and Recommendations, *continued*

- States should be offered incentives and technical assistance with developing electronic filing and reporting systems that collect basic information about guardianships from the moment a petition is filed. A searchable, computerized system for aggregating information on adult guardianship cases would not only yield better usable data on guardianships, but would also improve that ability of courts to monitor and audit individual guardianships. Systems such as the "My Minnesota Conservator" reporting and data project are already in use in a few states and could be adopted across the country. Data collected must be detailed enough to allow for drawing conclusions and should include demographics, type of guardianship (limited vs. plenary, guardian over property vs. person, etc.), type of guardian (public guardians, private professional guardian, family guardian), age at which the person was subject to guardianship, court audits, timeliness of reports, amount of funds/property in the estate, and the involvement of the person in federal programs (Social Security benefits, Supplemental Security Income [SSI], Medicaid, Medicare, VA benefits, etc.). The data should also include whether the initial petition was contested, whether there is any time limitation to the guardianship, and whether there is any periodic review of the continued need for guardianship.

Finding 2: People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions than other adults regardless of the actual impact of their disability on their cognitive or decision making abilities. This can lead to guardianship petitions being filed when it is not appropriate and to guardianship being imposed when it is not warranted by the facts and circumstances.

Recommendations:

- The Department of Justice (DOJ), in collaboration with the Department of Health and Human Services (HHS), should issue guidance to states (specifically Adult Protective Services [APS] agencies and probate courts) on their legal obligations pursuant to the Americans with Disabilities Act (ADA). Such guidance should address NCD's position that: 1) the ADA is applicable to guardianship proceedings; 2) the need for assistance with activities of daily living or even with making decisions does not give rise to a presumption of incapacity; and 3) guardianship should be a last resort that is imposed only after less restrictive alternatives have been determined to be inappropriate or ineffective.

(continued)

Findings and Recommendations, *continued*

- In January 2017, the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) issued school-to-adult transition-related guidance that recognized alternatives to guardianship, including the use of supported decision making (SDM) and powers of attorney for adult students with disabilities. While this policy development is promising, OSERS needs to do more to ensure consistent implementation of this guidance across state and local educational agencies—for example, the creation of model supported decision making and powers-of-attorney forms geared toward transition-age youth. School transition teams must inform parents/caregivers and students of less-restrictive decision making support options for adults, rather than promoting the overuse of guardianship or involuntary educational representatives.
- The Department of Education Office of Special Education Programs (OSEP) should instruct Parent Training and Information Centers to prioritize and provide meaningful training on school-to-adult transition and alternatives to guardianship.
- HHS should issue guidance regarding the responsibility of medical professionals and hospitals to accommodate the needs of individuals who may need assistance making medical decisions and to adequately explain procedures and draft documents provided to patients in plain language.
- Although the Federal Government generally leaves the content of medical school training to the accrediting bodies, federal advisory group recommendations, and federal grants from CMS, HHS, and other federal agencies can influence the content of medical training and curriculum. Educating medical professionals about the ADA and the need to accommodate people with disabilities, including those with intellectual disabilities and cognitive impairments, should be prioritized as a part of medical training.
- The National Home and Community-Based Services Quality Enterprise (NQE) should include decision making assistance and use of alternatives to guardianship such as supported decision making in their priorities and include best practices as part of its resources, training, and technical assistance.
- The Administration for Community Living (ACL) has funded numerous projects that are geared toward expanding alternatives to guardianship, such as supported decision making. The agency also provides state grants to enhance adult protective services. Such funding should be allocated specifically to assist state adult protective services systems to develop greater awareness of ways to enhance the self-determination of adults considered vulnerable or in need of services, as well as the availability and use of alternatives to guardianship.

Findings and Recommendations, *continued*

- The Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities (UCEDDs), and the Protection and Advocacy (P&A) organizations should link work that has been done on advancing the self-determination of people with intellectual and developmental disabilities (ID/DD) with avoiding guardianship. There needs to be recognition that the appointment of guardians is not necessarily the preferred outcome for people with disabilities. Such appointments instead can be the result of systems failing to fully recognize people's right to direct their own life and to support them in developing self-determination and communication skills, use and build natural support networks, and have access to less-restrictive alternatives. UCEDDs in particular have a role in educating physicians, medical professionals, and parents of people with ID/DD on self-determination, supported decision making (SDM), and other alternatives to guardianship.

Finding 3: People with disabilities are often denied due process in guardianship proceedings.

Guardianship is viewed as a benevolent measure that is sought in the best interest of people with disabilities and/or older adults who are seen as needing protection. Guardianship cases are often dispensed with as quickly as possible with little concern for due process or protecting the civil rights of individuals facing guardianship.

Recommendations:

- The Elder Abuse Prevention and Prosecution Act (P.L. 115-70) calls upon the Attorney General to publish best practices for improving guardianship proceedings and model legislation relating to guardianship proceedings for the purpose of preventing elder abuse. The Attorney General's model legislation should incorporate the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), including its provisions for preventing unnecessary guardianships.
- To ensure that due process requirements are met, it is especially important that alleged incapacitated individuals facing guardianship have qualified, independent legal representation that will advocate for the individual's desired outcome, especially if that person expresses a desire to avoid guardianship or objects to the proposed guardian. However, many courts lack sufficient resources to fund this type of representation and families often find that such representation is cost-prohibitive. Federal grant money should be made available to help promote the availability of counsel.

(continued)

Findings and Recommendations, *continued*

- A state guardianship court improvement program should be funded to assist courts with developing and implementing best practices in guardianship, including training of judges and court personnel on due process rights and less-restrictive alternatives.
- The degree of due process provided in a guardianship matter should not be contingent on the type of disability that is the alleged cause of an individual's incapacity or inability to make and carry out decisions. The DOJ should take the position that such practices are discriminatory on the basis of the ADA.

Finding 4: Capacity determinations often lack a sufficient scientific or evidentiary basis.

Courts rely too heavily on physicians who lack the training, knowledge, and information needed to make an accurate determination.

Recommendations:

- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), National Institutes of Health, and other agencies that fund scientific research should provide grants to researchers who are trying to develop a better understanding of how people make decisions and how a variety of conditions—such as dementia, intellectual disabilities, brain injuries, and other disabilities—impact the ability of individuals to make and implement informed decisions.
- *Capacity* is a social and legal construct that is not necessarily provable or disprovable through scientific methods. Resources also should be geared toward developing functional approaches to capacity assessments that take into account the possibility that someone may need decision making assistance but not necessarily a surrogate or substitute decision maker.

Finding 5: Guardianship is considered protective, but courts often fail to protect individuals.

In some cases, guardians use their position to financially exploit people or subject them to physical neglect and abuse. Courts lack adequate resources, technical infrastructure, and training to monitor guardianships effectively and to hold guardians accountable for the timely and accurate submission of required plans, accountings, and other reports, as well as for conforming to standards of practice for guardians.

Findings and Recommendations, *continued*

Recommendations:

- The court improvement program proposed earlier could also enhance the ability of courts to monitor guardianships and should include the adoption of programs such as My MNConservator, which requires guardians to file reports electronically, allows for the flagging potential problems in filed accountings, and facilitates the periodic audit of guardianship files.
- Although professional and family guardians can both be the perpetrators of abuse in guardianship, there have been several high-profile cases of abuse by professional guardians. In most states, these professionals operate with minimal oversight except by the court. States should be provided with incentives to establish statewide boards that can provide for the accreditation and oversight of professional guardians.
- States should require family guardians to undergo training to ensure they understand their ongoing responsibilities to the person subject to the guardianship and to the court.

Finding 6: Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often do little to enforce this requirement.

Courts often find that no suitable alternative exists when, in fact, supported decision making or another alternative might be appropriate.

Recommendations:

- ACL currently funds the National Resource Center for Supported Decision-Making and several demonstration projects at the state and local levels. These grants should be expanded to be able to fund more geographically- and demographically-diverse projects and pilots that specifically test SDM models and use SDM and the court systems to restore people's rights as a matter of law, particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.
- The DOJ should make funding available to train judges in the availability of alternatives to guardianship including, but not limited to, supported decision making. This training should also include information about the home and community-based–services system and the workforce development system so that judges understand the context in which decisions are being made by and for people with disabilities. See Finding 3.

(continued)

Findings and Recommendations, *continued*

- It's important that states adopt provisions of the UGCOPAA that recognize alternatives to guardianship can be used in place of guardianship even when it is determined that the individual meets the definition of incapacity. DOJ should develop guidance to this effect.

Finding 7: Every state has a process for restoration, but this process is rarely used and can be complex, confusing, and cost-prohibitive.

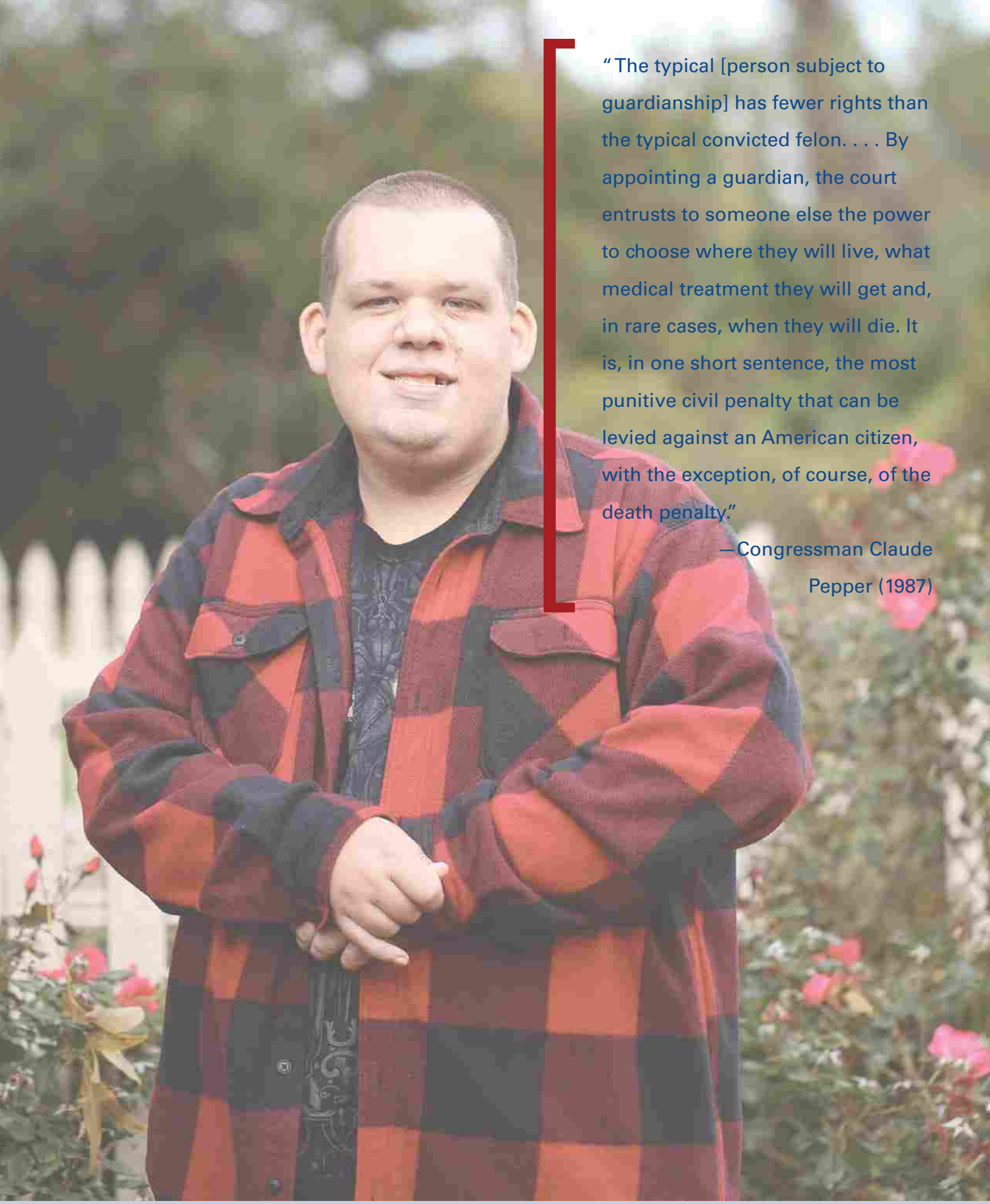
Data on restorations is seriously lacking, making it impossible to tell how many individuals are in unnecessary guardianship or whether individuals who would like to try to have their rights restored have access to information about their right to restoration, receive an appropriate response to their request for restoration, or have access to resources and representation to assist them in that effort.

Recommendations:

- As a part of the effort to improve data collection and monitoring, electronic filing and auditing systems ought to include data about restoration, including whether the individual was given information about restoration and whether the continued need for guardianship was reviewed by the court.
- The state court improvement program referenced throughout these recommendations should include improvements to the restoration process. DOJ should publish guidance regarding the right to restoration and best practices.
- A grant should be given to the Protection and Advocacy system to provide legal assistance to individuals who are trying to have their rights restored or avoid guardianship.

List of Acronyms

ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADAA	ADA Amendments Acti of 2008
AIP	alleged incapacitated person
AP	Associated Press
APS	Adult Protective Services
CMS	Centers for Medicare and Medicaid Services
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DOJ	U.S. Department of Justice
EAHCA	Education for All Handicapped Children Act
FHAA	Fair Housing Amendments Act of 1988
HCBS	Medicaid Home and Community-Based Services
HHS	Department of Health and Human Services
ID/DD	intellectual and developmental disabilities
IDEA	Individuals with Disabilities Education Act
IEP	individualized education program
NCD	National Council on Disability
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NQE	National Home and Community-Based Services Quality Enterprise
OSEP	Department of Education Office of Special Education Programs
OSERS	U.S. Department of Education Office of Special Education and Rehabilitative Services
P&A	Protection and Advocacy
SAMHSA	Substance Abuse and Mental Health Services Administration
SDM	supported decision making
SSA	Social Security Administration
SSI	Supplemental Security Income
UCEDDs	University Centers for Excellence in Developmental Disabilities
UGCOPAA	Uniform Guardianship, Conservatorship & Other Protective Arrangements Act
UGPPA	Uniform Guardianship and Protective Proceedings Act
VA	U.S. Department of Veterans Affairs
WINGS	Working Interdisciplinary Networks of Guardianship Stakeholders



"The typical [person subject to guardianship] 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 course, of the death penalty."

—Congressman Claude Pepper (1987)

Chapter 1: Guardianship Basics

Guardianship Fundamentals

Questioning the Assumptions of Guardianship

According to the National Guardianship Association, Inc.: "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. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after alternatives to guardianship have proven ineffective or are unavailable."[8]

[O]nce someone is declared incapacitated and is appointed a guardian, many of their rights are taken away and their ability to make decisions in a wide variety of areas given to another person.

Before we can begin evaluating guardianship or making recommendations for how to improve it, it is important to define and ensure a basic understanding of what guardianship is. Although the previous quote may seem like a reasonable definition from which to start, it contains value judgments—which are worthy of consideration—such as what constitutes "safe or sound decisions"; who gets to make that determination for an individual; and how an individual's safety should balance against his or her right to experience the dignity of risk.

Despite the oft-cited proposition that all people have certain inalienable rights, once someone is declared incapacitated and is appointed a guardian, many of their rights are taken away and their ability to make decisions in a wide variety of areas given to another person. Therefore, although guardianship is largely a creature of state law, it nonetheless raises fundamental questions concerning federal civil rights and constitutional due process. An adult usually becomes subject to guardianship when the court finds that:

- the individual is incapable of making all or some of their own financial or personal decisions, and
- it is necessary to appoint a guardian to make those choices on their behalf.

Rights at Risk in Guardianships

Guardianships are typically separated into two categories, guardianships of the person and guardianships of the property (also sometimes referred to as *conservatorship*). When the

REMOVABLE RIGHTS UNDER GUARDIANSHIP

…that *cannot* be exercised by another person

Marry

Vote

Drive

Seek or Retain Employment

…that *can* be exercised by another person

Contract

Sue and Defend Lawsuits

Apply for Governemnt Benefits

Manage Money or Property

Decide Where to Live

Consent to Medical Treatment

Decide with Whom to Associate or be Friends

…that can be exercised by another person *only with a court order*

Committing Someone to an Institution

Consenting to Experiments

Filing for Divorce

Consenting to Termination of Parental Rights

Consenting to Sterilization or Abortion

When Does an Adult Become Subject to Guardianship?

An adult usually becomes subject to guardianship when the court finds that:

- the individual is incapable of making all or some of their own financial or personal decisions, and
- it is necessary to appoint a guardian to make those choices on their behalf.

guardian controls decisions regarding both person and property, the guardianship is called *plenary*. However, there are really three types of rights that are at issue in guardianships:

- Rights that can be taken from an individual but not given to another individual
- Rights that can be taken from a person and exercised by someone else on their behalf
- Rights that a guardian needs a court order to exercise on the individual's behalf

Types of Rights at Issue in Guardianships

- Rights that can be taken from an individual but not given to another individual
- Rights that can be taken from a person and exercised by someone else on their behalf
- Rights that a guardian needs a court order to exercise on the individual's behalf

A person who is determined *incapacitated* generally can have the following rights removed, but these rights cannot be exercised by someone else. These include the right to:

- marry,
- vote,
- drive, or
- seek or retain employment.

Still, other rights can be removed and transferred to a guardian who can exercise these rights on behalf of the individual, such as the right to:

- contract,
- sue and defend lawsuits,
- apply for government benefits,
- manage money or property,
- decide where to live,
- consent to medical treatment, and
- decide with whom to associate or be friends.

In many states, there are also some rights that a guardian can exercise on behalf of the individual subject to guardianship, but only after the court has issued a specific order allowing the action, such as:

- committing the person to a facility or institution,
- consenting to biomedical or behavioral experiments,
- filing for divorce,
- consenting to the termination of parental rights, and
- consenting to sterilization or abortion.

This list is a general description of the way various rights are treated under guardianship laws across the country; for state-specific information consult the table in Appendix A for a reference to guardianship laws in each state.

A Word on Language

When a petition is filed with the court that alleges that the individual is incapacitated, the individual is often referred to as the *alleged incapacitated person*, or *AIP* for short. If the court finds that the person does lack capacity and appoints a guardian to manage some or all of their affairs, the individual is often referred to as the *ward*. In this report, we will use the term *AIP*, but because the term *ward* is viewed by many as stigmatizing and inappropriate, whenever possible, consistent with NCD's longstanding commitment of avoiding stigmatizing language, we will refer to individuals for whom a guardian has been appointed as an *individual subject to guardianship*. This is also consistent with the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), which is the latest iteration of the uniform guardianship statute that has been approved by the Uniform Law Commission.[9] However, it should be noted that the term *ward* will appear when it appears in a direct quote.

Process of Obtaining Guardianship

Overview

Guardianship petitions may be filed in a wide variety of situations: by parents when a child with an intellectual disability turns 18; by a son or daughter when a parent begins to show

signs of dementia severe enough that there is concern for their safety; for a person with a severe disability due to sudden trauma; or when there is concern that a bad actor is exercising undue influence over a person with a disability in order to exploit the individual in some way. There are also times when guardianship is filed for less altruistic reasons, such as to gain access to the person's assets or public benefits or to exploit the individual. Whether the guardianship is over person, property, or both, or whether it is limited or plenary may be determined, at least in part, by the circumstances that give rise to the perceived need for guardianship. Due to our federalist system of government, guardianship is a creature of state, rather than federal law, and all 50 states and the District of Columbia have revised their statutes regarding guardianship numerous times. However, it is not clear that in statute or in practice guardianship law has been able to keep pace with the nation's changing understanding of disability, autonomy, and due process.

Although the process is different in every state, making it difficult to provide a singular description of the guardianship process, there are certain generalities that are helpful to discuss before examination of whether or not guardianship is working for people with disabilities, their families, and communities. The following steps are generalities that may or may not align with the laws in a given state, so it is important for interested individuals to consult their state's laws for more accurate, detailed information.

[I]t is not clear that in statute or in practice guardianship law has been able to keep pace with the nation's changing understanding of disability, autonomy, and due process.

General Steps to Guardianship

1. Filing the petitions
2. Notice that a guardianship petition has been filed
3. Appointment of an attorney to represent the alleged incapacitated person
4. Capacity evaluation
5. Hearing
6. Letters of guardianship
7. Guardianship plan and initial reports

Steps to Guardianship

Step 1—Filing the petitions

In virtually all states, the guardianship process begins with filing a petition in the court with jurisdiction that alleges that a named individual is incapacitated and needs a guardian. In some jurisdictions, these are two separate petitions that actually result in two cases going forward. In Florida, for example, the petition for a determination of capacity commences a confidential proceeding and the court file of the case remains confidential as it invariably contains personal and medical information. However, the guardianship petition commences a public proceeding and the ultimate establishment of the guardianship is necessarily public information since the role of the guardian is to engage with others on behalf of the individual subject to

guardianship. From that point in the process until the person is determined to lack, or not lack, capacity, the named individual is known as the AIP. Once a guardian is appointed, the individual is generally referred to as the *ward*, although, as noted previously, we will use *individual subject to guardianship* throughout this report. Usually the petitioner knows the AIP well, and is often a parent, an adult child, or a social worker for the AIP. Generally speaking, most jurisdictions require that the following basic information be provided to the court in the petition:

- A description of the nature and type of disability of the AIP and how it impacts the individual's decision making
- Any relevant medical documentation to which the petitioner has access
- A statement asserting the need for guardianship and justifications supporting this opinion
- The suggested guardian's name, who must be a person who is willing and statutorily qualified (e.g., over 18, not a felon), with a description of his or her relationship to the AIP
- the name of the person or facility that is providing care for or has custody of the AIP; and
- the name of the proposed guardian or his or her attorney (some states require the guardian to be represented).

Additionally, many states recognize that someone who is facing guardianship may have difficulty understanding the notice they are given. In these states, there are statutory requirements that attempt to ensure that the person has the best chance of understanding the information. For example, in Virginia, the AIP must receive a brief statement in at least 14-point type of the purpose of the proceedings, his or her right to counsel and to a hearing, and a statement warning him or her in bold capital letters that the hearing may result in the individual losing many of his or her rights and a guardian being appointed to make decisions for him or her.[10] Another example is in Florida, where an attorney is appointed by the court as soon as the petition is filed, and that attorney is required to visit the individual within 24 hours of the filing of the petition to read the petition to him or her and explain exactly what it means.[11]

Step 2—Notice that a guardianship petition has been filed

Most states require that certain interested parties such as next of kin, existing "attorney-in-fact," or health care proxy receive notice that a guardianship or determination of capacity petition has been filed. This notice usually includes:

- the name of the AIP;
- the names of the AIP's closest relative(s);

Step 3—Appointment of an attorney to represent the AIP

The right to counsel is a basic procedural right of respondents in guardianship proceedings. The Uniform Guardianship and Protective Proceedings Act (UGPPA) and the National Probate Court Standards both require appointment of counsel to represent the AIP, and most states have put these provisions into practice. However, the role of the attorney varies significantly from state to state, "with some states requiring counsel as

vigorous advocate and others specifying that counsel should act as guardian ad litem."[12]

Legal representation should be seen as necessary in all guardianship proceedings—even under the most benevolent and caring circumstances—because guardianship represents a deprivation of liberty, which implicates due process.[13] The role of legal counsel in guardianship proceedings raises a number of interesting questions and will be discussed in greater detail later, with a close examination in Chapter 6.

Step 4—Capacity evaluation

The procedures for determining capacity vary a great deal from state to state and sometimes depend on the type of incapacity that is alleged.[14] Generally, the determination that an individual lacks capacity will be informed by an evaluation by an expert; this is discussed in greater detail in Chapter 5. As will be discussed in Chapter 5, some states also have separate procedures for people with developmental disabilities.[15] Additionally, a few states provide examiners who are called upon to make capacity determinations after receiving specialized instruction or training in how to make such a determination under the state law.[16]

Step 5—Hearing

Generally, the guardianship hearing occurs within a relatively short period of time following the petition and the capacity evaluation.[17] Because some courts now recognize that capacity may change over time, the information and evidence the court will use to make a decision regarding the need for guardianship should be contemporary in order to serve as relevant evidence.[18] Usually, there is a requirement that all interested parties, including the AIP, next of kin, and possibly others have received notice and know when and where the hearing will be. Finally, most jurisdictions require the AIP to be physically present at the hearing unless the judge determines there is good cause for them not to be there.

Guardianship hearings can be very brief and uncomplicated if the court determines the capacity evaluation presents clear and convincing evidence that the individual lacks capacity, if the AIP does not dispute or agrees to a guardian, and if the court and AIP agree on who the guardian should be. However, the hearings can also become fairly adversarial with witnesses being called and contradicting evidence presented if there is disagreement about whether the individual is incapacitated or who should be appointed guardian.

Step 6—Letters of guardianship

If the court determines that the individual is incapacitated, the judge generally will enter a judgment describing the incapacity and issue letters of guardianship, which outline the extent of the guardian's authority and outline his or her duties and responsibilities. At this point, the AIP becomes an individual subject to guardianship. In some states, guardians are required to have completed certain training and certification requirements prior to appointment. There are three broad types of guardians:

- Public guardians, who are publicly funded to provide guardianship services to individuals with no family willing to serve as guardian. In some states a public guardian is only appointed if the individual is indigent.
- Professional guardians, who are paid out of the estate of the individual subject to

guardianship or a court fund to provide guardianship services

- Family guardians, who are usually family members, but may also be unrelated friends who are not acting as guardians for multiple individuals

Generally, guardians—even family guardians—can be reimbursed out of the estate of the individual subject to guardianship for activities on behalf of the individual such as paying bills, consulting with medical professionals, or making living arrangements. As the name suggests, professional guardians provide these services to large caseloads of individuals subject to guardianship and are paid, usually after authorization from the court, out of the individual's assets. Payment is generally only authorized by the court at a rate the court deems "reasonable," which may differ from jurisdiction to jurisdiction within the state depending on prevailing rates for professional services. Additionally, what is reasonable may depend on the task performed and the level of expertise required. This is will be discussed in greater detail in Chapter 6.

Step 7—Guardianship plan and initial reports

There are best practices outlined by organizations such as the National Guardianship Association and a few initial steps that most guardians take—as determined by state law. The specific requirements may depend on whether the guardianship is over person, property, or both. One of the first steps of a guardian of the property is to determine what assets and liabilities the individual subject to guardianship has and to make an initial report to the court providing a summary of their finances. In many jurisdictions, annual reports, including a detailed accounting of how the money of the individual subject to guardianship is being spent, are required as long as a guardianship of the property is in place.

For guardians of the person, many jurisdictions require the guardian to submit a plan soon after appointment that describes his or her proposed plan of care for the individual subject to guardianship as well as history of past care. These plans may be reviewed by the judge overseeing the case, by the clerk of the court, or by a court monitor appointed to assist the court with oversight. This provides a baseline that enables the court to measure the guardian's future performance. Some jurisdictions require that a guardian be represented by an attorney who ensures that the annual accountings and reports are filed accurately and timely. A guardian's attorney may work at the direction of the guardian, but he or she has a fiduciary responsibility to the individual subject to guardianship and can be held accountable for mismanagement of funds, misrepresentations to the court, or any action that is contrary to the best interest of the individual subject to guardianship.[19]

Court Determination of Incapacity

Generally speaking, a person who is incapacitated has been determined by a court to be "unable to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care."[20] It should be noted that the word *incapacitated* is essentially interchangeable with the word *incompetent*, which used to be the preferred term. This change in parlance occurred largely due to reforms that began in the 1980s and

continue to this day.[21] Although there is quite a bit of debate in scholarly circles about the semantic differences in the two terms, it is enough to understand that being declared incompetent is associated with a time when the law declared an individual to be an "idiot," "lunatic," "person of unsound mind," or "spendthrift," and therefore generally "incompetent" and unable to exercise any rights.[22] *Incapacitated,* on the other hand, is the current term used by most courts that employ a combination of medical and functional criteria to reach a determination that a person cannot exercise specific rights. The court generally applies a two-pronged legal test to determine whether an individual is incapacitated.[23] The court must make two findings:

1. The existence of a disabling condition, such as "mental illness," "mental disability," "intellectual disability," "mental condition," "mental infirmity," or "mental deficiency."
2. That such condition causes an inability to adequately manage one's personal or financial affairs.[24]

Two-Step Legal Test to Determine Incapacity

The court must make two findings:

1. The existence of a disabling condition, such as "mental illness," "mental disability," "intellectual disability," "mental condition," "mental infirmity," or "mental deficiency."
2. That such condition causes an inability to adequately manage one's personal or financial affairs.

[I]t is enough to understand that being declared incompetent is associated with a time when the law declared individuals "idiot," "lunatic," "person of unsound mind," or "spendthrift" . . .

Capacity and Scope of the Guardian's Authority

Although it used to be the case that guardians were appointed to exercise virtually all the rights of the individual subject to guardianship, it is now possible for judges to decide that a person can exercise some rights but not others on their own.[25] For example, a person may be able to understand medical information and make informed decisions based on that information but not be able to remember to pay their bills on time. Such a person may retain the right to make medical decisions but lose the right to manage property or sign contracts. This arrangement is called a *limited guardianship.* As one woman who has guardianship over her adult daughter with disabilities put it, "[s]he doesn't really understand the concept of money but as far as decisions [about] where to live, what to eat, where to go, what entertainment to do, she makes all those decisions." Conversely, when an individual is determined to lack capacity to exercise *any* of the rights described at the beginning of this chapter, the guardianship is considered *plenary* or *general.*

In many states, there is an explicit statutory preference for limited guardianship that only gives the guardian the right to make decisions

the individual is truly incapable of making. Unfortunately, as we will explore in Chapter 4, empirical studies indicate that courts do not often take advantage of the limited guardianship option and rarely limit a guardian's authority.[26]

Lawyers and judges who work in the area of guardianship will also sometimes refer to a *guardian of the person* or a *guardian of the property*. In some states, guardianship of the property is sometimes referred to as *conservatorship,* but we will continue to use the more generic and descriptive term *guardianship of the property* to refer to these arrangements throughout the report. All these terms simply indicate whether or not the guardian has been given authority to manage any personal affairs or make medical decisions for the individual subject to guardianship, the authority to manage the individual's property, or both.[27] A *plenary guardian* is generally considered the guardian of both person and property.[28]

Although a determination of incapacity is a legal decision made by a judge, "[t]he court customarily evaluates the medical condition of the proposed individual subject to guardianship by considering the individual's medical history, any diagnosis of mental illness [or other impairment], and a psychological evaluation."[29] In many cases, the determination of incapacity and the need for a guardian (as opposed to using a less restrictive alternative) must be proved by clear and convincing evidence.[30] One final factor that can impact the scope of the guardian's authority is whether the guardian makes decisions on behalf of the individual based on a "substituted judgment or best interest" standard; in some jurisdictions the statute or case law will specify which standard should be used and under what circumstances. The substituted judgment standard takes into account the individual's preferences, beliefs, and patterns of behavior as well as the individual's wishes, which may have been expressed when the individual had capacity. While the "best interest" standard should also include a consideration of these factors, it is generally more geared toward making decisions the guardian believes are in the individual's best interest with the person's well-being, health, and safety being the central concerns. These standards not only impact how the guardian makes decisions, but also how a court might review those decisions.

[E]mpirical studies indicate that courts do not often take advantage of the limited guardianship option and rarely limit a guardian's authority.

Ending a Guardianship

Once a guardianship is put in place, in most circumstances, it lasts either until the individual subject to guardianship dies, until all of his or her rights are restored, or until it is determined by the court that, although the person continues to lack capacity with regard to one or more of the rights that had been removed, there is a less restrictive alternative that will protect the individual's property and/or health and welfare without the need for a guardian. If the guardian dies and a court has not restored the individual's rights or found a less restrictive alternative appropriate, a successor guardian is appointed to replace him or her.

Unfortunately, restoration of rights is an alarmingly rare occurrence. This will be discussed at greater length in Chapter 7, but for now, it is enough to understand that all states have a process for restoration of the rights of the individual subject to guardianship. Usually, either the individual or another interested party can ask the court to restore some or all of the rights that were removed when the guardianship was established. The procedures vary from state to state, but in many cases, the court will convene a hearing regarding restoration and receive evidence, sometimes including an independent capacity evaluation, and make a ruling regarding whether some or all of the individual's rights should be restored. A court order will specify which of the individual's rights were restored. If property rights are restored, generally the guardian of the property is required to file a final accounting and "wrap-up" the guardianship by providing any documents the individual will need to regain control of his or her property and assets.

Unfortunately, restoration of rights is an alarmingly rare occurrence.

In the event that the guardianship ends because the individual subject to guardianship dies, the guardian will have to file the death certificate with the court within a specified period of time and relinquish control of the "guardianship estate" to the executor of the individual's will or the individual's next of kin. Finally, the guardian may be required to file a final accounting that identifies how assets in the guardianship estate have been managed since the last accounting as well as where assets are to be found with the court that had overseen the guardianship.

Chapter 2: Guardianship Against the Backdrop of Disability Rights Law

The table that follows originally appeared in NCD's *Rising Expectations: The Developmental Disabilities Act Revisited* report and has been updated.[31]

Table 1. Timeline of Major Legislative and Policy Initiatives Affecting People with Developmental Disabilities, 1960–2010

1960–1965	▪ President Kennedy delivers a Message to Congress, calling for a "bold new approach" in the United States for responding to people with mental illnesses and intellectual disabilities and releases the *National Plan to Combat Mental Retardation.* ▪ The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 creates a national network of research centers and university-affiliated facilities. ▪ The Social Security Act of 1965 establishes the Medicare and Medicaid programs.
1966–1970	▪ The number of residents in large state institutions for people with intellectual disabilities reaches its peak at 194,650 in 1967.
1971–1975	▪ In 1971, amendments to Title XIX of the Social Security Act authorize Medicaid reimbursements for intermediate care facility services. ▪ The Civil Rights Division of the U.S. Department of Justice begins intervening in disability rights cases, starting with a judge's invitation in *Wyatt v. Stickney.* In *Wyatt,* 325 F.Supp. 781 (M.D. Ala. 1971), a federal court held for the first time that people with mental illnesses or intellectual disabilities who are involuntarily committed to state institutions have a constitutional right to treatment that will afford them a realistic opportunity to return to society. ▪ The Social Security Amendments of 1972 establishes the Supplemental Security Income (SSI) program for seniors and people with disabilities. ▪ The Rehabilitation Act of 1973 revises earlier vocational rehabilitation legislation to emphasize serving people with severe disabilities and includes a nondiscrimination clause (see 1976–1980). ▪ The Education for All Handicapped Children Act of 1975 mandates that children with disabilities ages 3–21 receive a free and appropriate education in the least restrictive environment based on an individualized education program and with due process guarantees.

(continued)

1971–1975	▪ On May 5, 1975, the New York Governor signed the Consent Decree that ended the legal battle to improve conditions at the Willowbrook State School in Staten Island, New York. The Decree established that residents of Willowbrook had a constitutional right to be protected from harm and required New York state to take immediate steps to improve the lives of those who lived there and to "ready each resident . . . for life in the community at large" in the "least restrictive and normal living conditions possible."
1976–1980	▪ Regulations implementing Section 504 of the Rehabilitation Act of 1973 are signed in 1977, implementing the nondiscrimination clause that prohibits the exclusion of people with disabilities from any program or activity receiving federal financial assistance. ▪ A U.S. District Court found that residents of the Pennhurst institution had three distinct sets of constitutional rights, including the right to habilitation, the right to be free from harm, and the right to nondiscriminatory and nonsegregated habilitation.
1980–1985	▪ The Medicaid Home and Community-Based Services (HCBS) waiver program is established. ▪ The Civil Rights of Institutionalized Persons Act of 1980 provides the DOJ with the statutory authority to bring cases to protect people living in institutions.
1986–1990	▪ 1986 Amendments to Education for All Handicapped Children Act provide funding to states to offer early intervention programs for infants and toddlers. ▪ The Technology Related Assistance for Individuals with Disabilities Act of 1988 establishes grant programs to encourage the development and distribution of assistive technology for people with disabilities. ▪ The Fair Housing Amendments Act (FHAA) of 1988 amended Title VIII of the Civil Rights Act of 1968, which prohibits discrimination on the basis of race, color, religion, sex, or national origin in housing sales, rentals, or financing. The FHAA extends this protection to people with disabilities and families with children. ▪ The 1990 Americans with Disabilities Act prohibits discrimination based on disability.
1991–1995	▪ The 1992 Education for All Handicapped Children Act is changed to Individuals with Disabilities Education Act (IDEA), and language is added to support the transition from school to adulthood.
1996–2000	▪ The Ticket to Work and Work Incentives Improvement Act of 1999 establishes new programs and work incentives for SSI and Social Security Disability Income beneficiaries. ▪ In 1999, the U.S. Supreme Court holds in the case of *Olmstead v. L.C.* that the unnecessary segregation of people with disabilities in institutions may constitute discrimination based on disability. This case had and continues to have significant public policy implications for people with disabilities.
2001–2005	▪ In 2001, the New Freedom Initiative includes a set of proposals designed to ensure that Americans with disabilities have the opportunity to learn and develop skills, engage in productive work, make choices about their daily lives, and participate fully in their communities. ▪ The No Child Left Behind Act of 2001 is designed to ensure that all children have a fair, equal, and significant opportunity to obtain a high-quality education and requires that states develop accountability systems.

2006–2010	▪ Congress enacts the ADA Amendments Act of 2008 (ADAA), making it easier for a person to establish that he or she has a disability within the meaning of the statute. Congress overturned several Supreme Court decisions that had interpreted the definition of *disability* too narrowly, resulting in a denial of protection for many people with impairments such as cancer, diabetes, and epilepsy. The ADAA states that the definition of *disability* should be interpreted in favor of broad coverage of individuals. ▪ The Convention on the Rights of Persons with Disabilities (CRPD) is an international disability treaty modeled on the ADA. The CRPD is a vital framework for creating legislation and policies around the world that embraces the rights and dignity of all people with disabilities. The United States signed the CRPD in 2009, but Congress has not yet ratified it.

Guardianship as a Disability Policy Issue

Guardianship is often overlooked, and, when it becomes part of the national policy conversation, it is often viewed as an issue impacting older Americans and not thought of as an important disability issue. However, guardianship must be understood as a disability policy issue worthy of examination, reflection, and reform. After all, an adult becomes subject to guardianship only if a court has determined that he or she cannot manage property or meet essential requirements for health and safety. Additionally, at least 11 states have laws that provide for alternate, and generally less rigorous, procedures when the individual who allegedly needs a guardian is an adult with intellectual and/or developmental disabilities. The Table of Authorities in Appendix A at the end of this report references the statutes that make this distinction. Regardless of whether one is a young adult with a congenital developmental disability subject to guardianship because the court determined he or she lacked the ability to make decisions him or herself, or whether one is in his or her 80s and the court believes that Alzheimer's disease has advanced to the point where he or she can no longer make decisions for his or herself, the reason to impose guardianship is disability in both instances.

[A]t least 11 states have laws that provide for alternate, and generally less rigorous, procedures when the individual who allegedly needs a guardian is an adult with intellectual and/or developmental disabilities.

In order to fully understand guardianship as a disability issue, we need to come from a common understanding of it within the context of the evolution of disability policy, particularly as it relates to issues of liberty, autonomy, and self-determination. This chapter provides an overview of the evolution of disability policy from the eugenics movement to the CRPD in order to provide context for our discussion of guardianship and to help ground our recommendations in NCD's long tradition of advancing policies that

promote the dignity, self-determination, and maximum independence of all people with disabilities regardless of their age.

History of Discrimination

The Eugenics Movement

Disability is a natural part of the human experience that has always been a part of the fabric of American society.[32] However, a movement that was an important part of American politics from the 1890s until the 1920s aimed specifically to remove people with disabilities and other minority groups from society.[33] The eugenics movement relied upon fear and pseudoscience to enact public policies to segregate people with disabilities from their families and communities and to impede their ability to procreate, so that their alleged "bad genes" would not burden society for another generation, as the narrative went.[34] Even those considered among the best legal minds of the age embraced the noxious policy of eugenics, including U.S. Supreme Court Justice Oliver Wendell Holmes Jr., who penned the infamous *Buck v. Bell* decision in 1927 and found state statutes permitting compulsory sterilization of people with disabilities were not unconstitutional.[35] Fortunately, the eugenics movement fell into public disrepute after discovery of the Nazis' horrific acts committed in reliance on eugenic ideas.[36] In fact, mass exterminations in Nazi Germany in the 1940s began with the killing of institutionalized Germans with disabilities in the T4 program—actions based on eugenic theories imported from the United States more than a decade earlier.[37]

While the end of World War II marked a de-escalation of the eugenics movement, many forcible sterilization laws, of which the eugenics movement had facilitated enactment, persisted well into the 1970s.[38] The policies that began during the eugenics movement's heyday reverberate through laws that are still on the books today and have a profound impact on American society's understanding of disability. As NCD pointed out in its 2012 report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children*, over two decades after the passage of the ADA, several states still have laws on their books that authorize involuntary sterilization and affirm in statute that the "best interests of society would be served by preventing them [people with disabilities] from procreating."[39]

Eugenics attempted to control whether people with disabilities made fundamental decisions for themselves about having intimate relationships and children; during the same time period many individuals were denied the right to determine where and how to live because they were committed to large state institutions.

Underlying these historic laws and other practices to be described later in this chapter is a base assumption that people with disabilities are incapable of making decisions for themselves, and that society must be protected from the consequences of the decisions that people with disabilities might make. Eugenics attempted to control whether people with disabilities made

fundamental decisions for themselves about having intimate relationships and children; during the same time period many individuals were denied the right to determine where and how to live because they were committed to large state institutions.

Institutionalization

As a result of state statutes authorizing involuntary sterilization in 30 states, by 1970 more than 65,000 Americans had been involuntarily sterilized, and to this day several states have not removed these statutes from their books.[40] In addition to the practice of eugenic sterilization, from the mid-1800s through the early 1970s, states regularly practiced segregation of people with disabilities via institutionalization, which also represented a fundamental violation of their human rights.[41] With respect to people with intellectual disabilities, these sprawling institutions started in many cases as benevolent organizations with a mission to impart a "practical education" to the students who were expected to one day return to their communities as productive members. However, as early as the late 1850s, the goal of the institutions had already become strictly custodial in nature. People with disabilities placed in them were effectively warehoused away from the rest of society, and few individuals who found themselves living in them could ever expect to leave them in their lifetimes.[42] As the goals of these institutions shifted, fewer resources were directed at providing for a quality of life for the people who resided there. Any federal money available to states was only available for purposes of building the facilities, and between 1950 and 1970, there was a building boom of these institutions in which states built, refurbished, or expanded institutions more than during any other time in American history. Despite the high level of building investment, by the 1960s, the largest institutions had become chronically understaffed, overcrowded, and underfunded.[43] In particular, the horrific conditions at Willowbrook—the largest facility for people with intellectual and psychiatric disabilities in the country that housed more than 6,000 people—prompted U.S. Senator Robert Kennedy to call the New York institution a "snake pit" in 1965.[44] While Kennedy's commentary brought about some minor changes at Willowbrook and other facilities of its kind, it was not until the media picked up the story in the late 1960s and early 1970s that Americans were confronted with the extent of the country's moral failure to uphold the humanity of people with psychiatric and intellectual disabilities.

[T]hese sprawling institutions started in many cases as benevolent organizations with a mission to impart a "practical education" to the students who were expected to one day return to their communities. . . . However, as early as the late 1850s, the goal . . . had already become strictly custodial in nature.

Geraldo Rivera famously exposed New Yorkers to the horrifying conditions inside Willowbrook, and Bill Baldini similarly brought the conditions at Pennhurst State Hospital into living rooms in Pennsylvania.[45] These reporters and others forced a nation to grapple with images that rivaled those that some remembered from black and white

newsreels following World War II. Americans now saw emaciated children who were unable to walk because they had never been lifted from their cribs, covered in flies, and lying in filth.[46] They saw adults with hollow eyes wandering aimlessly, often sedated to keep them compliant and under control.[47] These exposés led parents who had been told that they were doing the right thing by placing their children in the state's care to file lawsuits to improve the conditions at these facilities, and led legislatures to increase or restore funding to improve conditions.[48] Advocates and the legal community mobilized around these issues as well, working not only to improve the conditions in these large facilities, but also to ensure that people with psychiatric disabilities were afforded due process before being committed to a facility and to expand opportunities for integration in education and community services for people with intellectual disabilities.

Civil Rights Expansion and Joining the Community

Deinstitutionalization

The deinstitutionalization movement led to major shifts in disability policy and the cultural understanding of disability. Since people under adult guardianship—even those who are in the aging population—are people with disabilities by definition, these changes impacted guardianship laws, drove many of the guardianship reforms outlined in Chapter 3, and continue to drive guardianship reform conversations today. More directly, guardianship played an integral part in deinstitutionalization. Many individuals

who were slated to leave closing institutions were separated from their families as children. In order to move individuals who were determined to lack the ability to consent to new placements outside of the institutions, it was deemed necessary to find guardians who were willing to sign off on integrating them into the community.[49] However, for a variety of reasons including estrangement from family or not having family members who were appropriate guardians, one study found that 1,643 individuals in institutional placement in Florida between 1983 and 1985 were "incompetent" but did not have guardians who could help them with a move to a less restrictive setting.[50] On the other hand, guardians have sometimes objected to moving individuals under their care into the community. Recently, advocates trying to implement "Money Follows the Person" federal grants designed to help move individuals into community settings have found that it can be difficult to obtain guardian consent to move the individual into the community.[51] A report from the Connecticut experience with Money Follows the Person describes guardians who worry that their loved ones need 24/7 care, that they will not be able to access in the community, or that the guardian will be expected to manage services on a day-to-day basis.[52]

[A]dvocates trying to implement "Money Follows the Person" federal grants designed to help move individuals into community settings have found that it can be difficult to obtain guardian consent to move the individual into the community.

Independent Living

Around the same time that society was awakening to the neglectful and cruel treatment of people with psychiatric, intellectual, and developmental disabilities in large institutions, people with disabilities themselves were beginning to demand better treatment in other segments of society. In 1962, the University of California at Berkeley admitted Ed Roberts as a student but forced him to live in the campus medical facility due to his quadriplegia and reliance on a ventilator after contracting polio as a teenager.[53] Roberts organized his fellow students with disabilities on campus into a student group that began pushing the university to become more accessible and provide support services so that students with disabilities could live more independently.[54] Roberts and others went on to found the Berkeley Center for Independent Living. The core values they established, "dignity, peer support, consumer control, civil rights, integration, equal access, and advocacy," remain at the heart of the independent living and disability rights movements to this day.[55] People with disabilities, their families, and advocates who had worked with them and witnessed some of the injustices first hand began to assert the right of people with disabilities to live in the world, ". . . on the streets, the highways and byways, in public buildings, and other public places, in the schools and colleges, in the public service and private callings, in the factories, shops and offices, in short, in all the places where men are, go, live, work, and play . . ." and to demand that the laws work toward the goal of integration for people with disabilities.[56] People were awakening to the idea that people with disabilities could be fiercely

independent and, to the extent that they were viewed as dependent, that it might be a function of society's failure to accommodate their different needs rather than a condition that was inherent in one's physical or mental disability itself.

Once people with both physical and mental disabilities began to insist on their independence, guardianship as a legal construct came under scrutiny. Guardianship is a protective measure that is predicated on the idea that people with disabilities are incapable of caring for themselves and that they need others to make decisions for them about their care, relationships, and other aspects of everyday life. One interviewee described it in the following way: "One other thing that is to me most frustrating is that the general public does not think of guardianship in increments . . . [W]hen you say guardianship, they think that the person can't do anything . . . [They] will start speaking directly . . . to the guardian as opposed to the individual."

People were awakening to the idea that people with disabilities could be fiercely independent and, to the extent that they were viewed as dependent, that it might be a function of society's failure to accommodate their different needs. . . .

Rehabilitation Act

The Rehabilitation Act of 1973 was one of the earliest federal laws to recognize the civil rights of people with disabilities, providing that, "No otherwise qualified [person] with a disability in the United States . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."[57] This kind of legislative language and much of the original law's stated purposes to "prepare [those with the most severe disabilities] for and engage in gainful employment" and to "improve [people with disabilities'] ability to live with greater independence and self-sufficiency" was a marked departure in tone from the laws passed during the eugenics movement that presumed disability equated with burden and incapacity.[58]

Although the Rehabilitation Act had the potential to reduce discrimination against people with disabilities in education, employment, housing, transportation, medical care, and access to public spaces, this potential went unrealized for many years as the community waited for the Department of Health, Education and Welfare (HEW) to publish regulations that would implement the law.[59] As noted in NCD's 2003 report, *Rehabilitating Section 504:*

> It took a nationwide sit-in at U.S. Department of Health, Education and Welfare (HEW) buildings by people with disabilities in 1977, including a month-long occupation in San Francisco, to persuade the Federal Government to issue regulations implementing Section 504 of the Rehabilitation Act.[60]

As demonstrated in advocacy leading up to the passage of the Rehabilitation Act and the sit-ins that preceded its implementation, during this time, people with disabilities were beginning to find their voice politically, insist that they speak for themselves, and demand equal access in society.

Developmental Disabilities Assistance and Bill of Rights Act

In the late 1960s and early 1970s, advocates for people with intellectual and developmental disabilities were busy working toward passing federal legislation that they hoped would shift federal funding away from institutions, build up resources in the community, and guarantee certain fundamental rights for people with intellectual and developmental disabilities (ID/DD). This activism led to the creation of Developmental Disabilities Councils, the Protection and Advocacy for Developmental Disabilities program that provided legal and advocacy services to protect people with ID/DD from abuse and neglect; and to the passage of the Developmental Disabilities Assistance and Bill of Rights Act in 1975, which was an amendment to the 1963 Mental Retardation Facilities Act.[61] The introduction of the DD Bill of Rights was one of the first times that the individual human rights of people with disabilities were expressly recognized in a U.S. law. It required that people with disabilities be included in forming habilitation plans and expressly granted this population with privacy rights and rights to free association in the context of receiving services—ideas that were unheard of when things like eugenic sterilization and segregation were the norm.[62]

During this time period, policymakers increasingly recognized that people with disabilities, particularly those with intellectual disabilities, had not always been provided the opportunity to make and learn from their mistakes; they were denied the experience of the dignity of risk. As one family member interviewed for this report expressed, "[O]ne of the things that happens frequently for people with disabilities is they just literally are not accustomed to making choices because nobody gives them the opportunity." Self-advocates and others argued that the focus on protecting people with disabilities, while important, is better accomplished when it is balanced with independence, personal autonomy, and the development of decision making skills. As another interviewee noted, "It's not about protecting someone. It's about teaching them how to best protect themselves."

[The DD Bill of Rights] . . . expressly granted . . . privacy rights and rights to free association in the context of receiving services—ideas that were unheard of when things like eugenic sterilization and segregation were the norm.

A Right to Public Education

Another important development that occurred during this time period was the Education for All Handicapped Children Act (EAHCA), which was later renamed the Individuals with Disabilities Education Act (IDEA). Passed in 1975, this law extended the right to a free and appropriate public education to children with disabilities who had often been denied entry into public schools.[63] Additionally, it gave children with disabilities the right to an individualized education program (IEP) designed by the school with input from their parents, and it gave parents of children with disabilities procedural due process rights that gave them an opportunity to ensure that their child's school was meeting its obligations.[64] IDEA and its predecessor EAHCA demonstrated

a dramatic shift in assumptions about what people with disabilities could expect from their lives. The expectation became a public education in integrated school settings that would prepare them for lives as independent adults, even if they continued to need services and supports into adulthood.

Community Integration

Section 504, the DD Bill of Rights Act, and EAHCA reflected a culture of changing expectations for people with disabilities; it was no longer unthinkable that children with intellectual disabilities would grow up to become integrated into the fabric of society and experience a sense of purpose. These changes were also taking place in a society that was experiencing massive cultural shifts in the 1960s and 1970s; many people whose human and civil rights had long been denied in the United States were being recognized as autonomous, self-determined actors worthy of full and equal recognition before the law.[65] These cultural changes made viewing people with disabilities as anything other than fellow human beings much more difficult, and it led to skepticism of cultural norms and traditional sources of authority who had been complicit in the oppression of women, people of color, the LGBTQ community, and others, including "a growing intellectual skepticism of psychiatry which posited mental illness as a social construct and therapeutic intervention as a means to impose social conformity."[66] This "outsider critique" of psychiatry led mental health advocates to push to raise the bar regarding due process, making it more difficult for the state to use its police power to restrict the liberty of people with psychiatric disabilities by committing them to psychiatric hospitals and state institutions.[67] Additionally, it fueled judicial decisions that raised the bar on civil commitments to the "danger to self and others" standard adopted by the Supreme Court in *O'Conner v. Donaldson*.[68]

Mental health advocates' approach was somewhat different than the approach of advocates for people with intellectual and developmental disabilities. While the due process arguments advanced by mental health advocates asserted a right to be free from unwanted treatment and from confinement, advocacy efforts for people with ID/DD were often led by families whose essential demand was for services as well as integration. While advocates in the psychiatric disabilities community often raised legal challenges to confinement and fought for stronger due process protections to prevent unnecessary confinement, advocates in the developmental disabilities community often argued:

The expectation became a public education in integrated school settings that would prepare them for lives as independent adults, even if they continued to need services and supports into adulthood.

- that if the need for treatment was the justification for confinement, that treatment needed to meet constitutionally mandated minimums in terms of quality; and
- that Section 504 of the Rehabilitation Act and the DD Bill of Rights Act of 1975

> contained an integration mandate that required services be provided in the least restrictive environment that would meet the needs of the individual.[69]

In other words, for people with psychiatric disabilities, advocacy focused on a right to be left alone, whereas for people with ID/DD, advocacy focused on a right to services in the community.[70]

One problem for people with ID/DD who want to receive services in the community rather than in institutional settings has been called the "institutional bias" in the Medicaid statute passed in 1965.[71] Simply put, under the Medicaid statute, treatment in an institutional care facility for the developmentally disabled and nursing care received in a nursing home are mandatory services that states must agree to pay for as a condition of accepting matching federal funds. However, there is no requirement in the statute that states provide home- and community-based services.[72] In 1981, the Omnibus Budget Reconciliation Act established the 1915(c) Home and Community Based Service Waivers (HCBS) program, allowing states to provide home- and community-based services to targeted groups of individuals as an alternative to institutional care.[73] While this statute did not create an entitlement to HCBS, it did create a funding mechanism that states have used to rebalance their Medicaid programs and provide more services in the community.[74] The waivers created a greater range of options for people with disabilities to receive supports that fit their needs and preferences and integrate in the community, and directed Medicaid providers to engage in person-centered planning with the people they served.[75] This range of options created a more consumer-driven system, which, in some ways, enhanced the decision-making authority of people with disabilities. However, paradoxically, this array of community options has potentially driven an increase in the number of guardianships because of the perceived need to have a decision maker to determine which services the person with ID/DD needs or wants, although this is difficult to quantify given the lack of data on guardianships discussed in Chapter 4.

As society continues to move toward greater community integration of people with disabilities, people with disabilities may need or want assistance making important decisions, such as where to live or work. Some may prefer that help to come from a guardian. One interviewee subject to guardianship reported, "I like having a guardian . . . they make sure that everything I do, I do the right way and they make sure that I'll be happy." Parents might also be concerned about the possibility not only that their children with disabilities will be unable to make choices about things like where to live and what services and supports they might need, but also that they might be vulnerable to exploitation or undue influence from individuals who are not acting in the best interest of their son or daughter. Parents who have advocated for their children with disabilities—often having to fight to get the school to provide the education their child was entitled to or to get the state Medicaid program to provide supports in the home and community—might understandably have a hard time imagining not making decisions for their children, whom they fear will not be able to advocate for themselves. These concerns might be driving what some have identified as an increase in the number of guardianships in the ID/DD population, but it's difficult to prove because of a lack of available

data on guardianships generally, as we will explore in Chapter 4.

The ADA Generation

In 1990, more than a decade after the DD Act and EAHCA, President George H. W. Bush signed the ADA into law. The ADA was first proposed in a 1986 groundbreaking report by NCD, *Toward Independence*.[76] The Council recommended that Congress "enact a comprehensive law requiring equal opportunity for [people] with disabilities, with broad coverage and setting clear, consistent, and enforceable standards prohibiting discrimination on the basis of handicap."[77] Unlike Section 504 of the Rehabilitation Act, which only outlawed discrimination on the part of programs receiving federal money, such a law would prohibit discrimination against people with disabilities in the same way that existing federal laws prohibited race and gender discrimination in virtually all areas of American life.[78] Furthermore, the integration mandate of Title II of the ADA requires that states provide services, activities, and programs in the most integrated and least restrictive setting appropriate to the needs of qualified people with disabilities.[79]

In 1999, nearly a decade after the signing of the ADA, the U.S. Supreme Court handed down the *Olmstead v. L.C.* decision interpreting the ADA.[80] The Supreme Court's decision in *Olmstead* has been described as similar in importance to the disability community as the *Brown v. Board of Education* decision was to the black civil rights movement.[81] *Olmstead v. L.C.* concerned two women with intellectual and psychiatric disabilities who had been deemed suitable for placement in the community by their doctors but had been denied the opportunity to move out of the Georgia state institution where they had lived for years.[82] The Court held that the unnecessary segregation of people with disabilities in institutions may constitute discrimination based on disability.[83] The Court further ruled that the ADA requires states to provide community-based services rather than institutional placements for people with disabilities if (a) community placement is appropriate, as determined by the state's professionals; (b) the transfer is not opposed by the affected individual; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported services.[84] The Supreme Court found that "[u]njustified isolation . . . [of people with disabilities] is properly regarded as discrimination based on disability," and thus violates the ADA.[85]

The Supreme Court found that "[u]njustified isolation . . . [of people with disabilities] is properly regarded as discrimination based on disability," and thus violates the ADA.

Since the Supreme Court affirmed in *Olmstead* that unnecessary segregation and isolation of people with any type of disability is discrimination and violates the law, there have been countless legal complaints and initiatives to implement the broad policy goals spelled out in the decision: to affirm the right of people with disabilities to live in the world and to provide services in the least restrictive environment.[86]

Many of the guardianship reforms discussed in this report will rely on the fundamental principles of integration and least restrictive environments, as required both in the text of the ADA and in the Supreme Court's interpretation of the ADA. As will be explored in Chapter 3 and also in Chapter 8, some scholars have argued that the integration mandate applies to guardianship and that guardianship itself may constitute a violation of the ADA in many cases.[87]

CRPD—The ADA Goes Global

In 2006, the CRPD was finalized and opened for signature and ratification.[88] The CRPD is an international treaty that was inspired by U.S. leadership in recognition of the rights of people with disabilities.[89] The CRPD is widely seen as an expansion of the ADA to the world stage, although in some of the particulars it is more informed by international human rights law than the American civil rights framework that formed the basis of the ADA. To date:

- 175 countries have ratified or accessioned it.
- 160 countries have signed it.[90]
- 92 countries have ratified and signed the Optional Protocol, which establishes a complaint mechanism for violations of the Convention.[91]

The United States signed the treaty in 2009 but has not yet ratified it. NCD has repeatedly called for the ratification of the CRPD and reaffirms that recommendation in this report.[92] The CRPD is a vital framework for creating legislation and policies around the world that embrace the rights and dignity of all people with disabilities. As we will see in the next chapter, it has had a profound impact in the countries where it has been ratified, including in the area of guardianship practices.

Chapter 3: Evolution of Guardianship Law

Table 2. Timeline of Major Legislative and Policy Initiatives for Guardianship Law, 1975–2017

1975–1985	▪ 1975: *O'Conner v. Donaldson* decision that led to standards of civil confinement ▪ 1978: The Model Guardianship Statute was developed. ▪ 1982: Uniform Guardianship and Protective Proceedings Act (UGPPA)
1986–1999	▪ 1987: The Associated Press (AP) published Guardians of the Elderly: An Ailing System, a series of reports on the failures of guardianship law and lack of oversight. ▪ 1987: The U.S. House Select Committee on Aging met to respond to the allegations laid out in the AP story. ▪ 1987: The National Guardianship Association formed. ▪ 1988: Held First National Guardianship Symposium "Wingspread" ▪ 1989: UGPPA was amended. ▪ 1997: UGPPA was revised.
2000–2010	▪ 2001: "Wingspan" conference took place at Stetson College of Law, Florida. ▪ 2006: United Nations Convention on the Rights of Persons with Disabilities (CRPD) ▪ 2007: The Uniform Guardianship and Protective Proceedings Jurisdiction Act ▪ October 4, 2010: Yokohama Declaration Adopted by the First World Conference on Adult Guardianship Law, Yokohama, Japan
2011–2017	▪ 2012: The Third National Guardianship Summit created the Working Interdisciplinary Networks of Guardianship Stakeholders (WINGS). ▪ 2012: New York County Surrogate Court decision, *In re Guardianship of Dameris L,* that terminated a guardianship in favor of supported decision making. ▪ 2013: New York, Oregon, Texas, and Utah piloted the WINGS groups. ▪ 2013: Virginia court decision, *Ross v. Hatch*, recognizes use of supported decision-making as an alternative to permanent plenary guardianship. ▪ 2016: The Elder Justice Innovation Grant expanded WINGS groups. ▪ 2017: UGPPA revised to UGCOPAA

Erica Wood, a noted expert in guardianship who is referenced throughout this report, has described guardianship as having a "front end" and a "back end."[93] The *front end* refers to the procedures for determining the individual's capacity and establishing the guardianship. The *back end* refers to the ongoing responsibility the guardian and the court have to the individual subject to guardianship, as well as the procedures for guardian oversight once the guardianship has been established. There is a long history of reform of both, particularly since the late 1980s. This chapter will trace the history of guardianship and guardianship reform and examine what reforms have already been tried and whether they have been successful. In some cases, these reforms are an integral part of ongoing issues in guardianship and will be discussed in greater detail later. Like the previous chapter, this chapter is not designed as a master class in guardianship reform; rather it is intended to survey the trends in guardianship law and highlight some of the issues in guardianship that led to these attempts to improve the system.

Ancient and British Roots

Guardianship may not be well understood in part because it is such a constant in our legal traditions. The son of the famous Greek playwright Sophocles attempted to obtain guardianship over his father as his health declined in his later years. Sophocles defended against the imposition of guardianship by reading from his latest play and the case was dismissed. Roman law allowed for the appointment of a "tutor" to manage the property of single women, orphans, and others who were not considered competent to manage property. However, the basis for American guardianship law is really British common law. Sometime in the late 1300s, the "royal prerogative" was enacted.[94] It described the king as the "father and guardian of his kingdom" and established that it was his responsibility "to take care of those who, by reason of their imbecility and want of understanding, are incapable of taking care of themselves."[95] Guardianship did not arise out of the spirit of altruism so much as from the need for the sovereign to make sure that land could remain in the hands of people who could dispose of it and otherwise exercise the rights of property ownership. Over the centuries, this royal prerogative evolved and the crown discharged its duty through agencies or private citizens who were appointed as curators or guardians.

Pre-Reform: Guardianship in America

American guardianship law is rooted in the royal prerogative as well, through its direct descendent the doctrine of *parens patriae*.[96] Parens patriae is Latin for "parent of the country," and refers to the role of the state in taking care of those who cannot care for themselves.[97] Federal power is derived from the Constitution, but under the 10th Amendment, powers not expressly granted to the Federal Government are reserved to the states, including the common law doctrine of parens patriae.[98] Therefore, guardianship remains a matter of state law. However, the state's authority to act under the doctrine of parens patriae is limited by constitutional requirements as well as other federal laws due to the "Supremacy Clause," which resolves conflicts between state and federal law in favor of the federal law.[99]

Initially, parens patriae was viewed as benevolent and there is little concern in early statutes with regard to due process. One scholar

noted, "the states have traditionally exercised their parens patriae powers in an atmosphere of informality. Relaxed procedures were said to be justified because the proceedings were non-adversarial; the sole preoccupation of the court was to serve the individual's best interest."[100]

However, in the 1960s, advocates for people with intellectual and psychiatric disabilities began to push to make it more difficult to justify the use of the police power, which confers upon states the authority to act to promote the health, safety, and welfare of the community and confine individuals to institutions. Additionally, advocates began to assert that the state had an affirmative duty to treat the disability that had been used to justify the individual's confinement rather than simply warehousing them in perpetuity.[101] Eventually this advocacy led to the development of the standard for civil commitment outlined in *O'Conner v. Donaldson* that states cannot constitutionally confine, "without more," a person who is not a danger to himself or others. The former category includes the suicidal and the "gravely disabled," who are unable to "avoid the hazards of freedom" either alone or with the aid of willing family or friends.[102] Subsequently, "all fifty states retooled their commitment laws to include adequate due process safeguards."[103]

In addition to making it more difficult to commit a person to a mental facility or institution, the Supreme Court recognized a constitutional right to minimally adequate training related to the person's liberty interest in avoiding unnecessary bodily restraint.[104] Although these cases concerned the police power and do not directly apply in guardianship cases, they did lead to a changed understanding of the constitutional implications of infringing on individual liberty due to disability or supposed incompetence.

Guardianship laws remained unchanged for more than 100 years and contained virtually no procedural due process protections. But in 1978, the American Bar Association developed a model guardianship statute, and in 1982, the Uniform Law Commission came out with the first UGPPA, now renamed the UGCOPAA.[105] The 1982 UGPPA was a groundbreaking document that emphasized autonomy and limited guardianship or conservatorship. However, it would be several more years before states began to look to these models to improve their guardianship statutes.

Guardianship laws remained unchanged for more than one hundred years and contained virtually no procedural due process protections . . .

Late 1980s, Early 1990s: First Wave of Guardianship Reform

As had happened a little over a decade earlier when Geraldo Rivera shined a much-needed light on the conditions at Willowbrook, the first significant wave of guardianship reform can be traced back to media attention on abuses within the system. In 1987, the Associated Press (AP) published a series of reports titled Guardians of the Elderly: An Ailing System, which splashed across front pages all across the country stories from "a dangerously overburdened and troubled system" that stripped seniors of their rights with the "stroke of a judge's pen," and subsequently failed to monitor the actions of the guardian or hold them accountable for the well-being of the individual subject to guardianship.[106]

The U.S. House Select Committee on Aging responded by convening a hearing where Chairman Claude Pepper famously observed the following:

> The typical [person subject to guardianship] 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 course, of the death penalty.[107]

In 1987, the Associated Press (AP) published a series of reports . . . [about] "a dangerously overburdened and troubled system" that stripped seniors of their rights with the "stroke of a judge's pen," and subsequently failed to monitor the actions of the guardian or hold them accountable.

Although Congress did not adopt reforms that year, in response to the public outcry that followed the AP story, most states began the process of reconsidering and revising their statutes. Additionally, the National Guardianship Association formed in 1987 and, shortly thereafter, developed first-of-its-kind standards of practice and a code of ethics for guardians.[108] The Congressional hearing also laid the groundwork for the First National Guardianship Symposium held in 1988. Known as "Wingspread," the conference brought together an interdisciplinary group of "judges, attorneys, guardianship-service providers, physicians, aging-network staff, mental-health experts, ethicists, academicians, and others . . ." who issued 31 recommendations for reform of the 50 different guardianship systems across the country.[109] These recommendations were relevant to every aspect of guardianship process, including procedural due process and legal representation, determining incapacity, and accountability of guardians.[110]

[T]he National Guardianship Association formed in 1987 and, shortly thereafter, developed first-of-its-kind standards of practice and a code of ethics for guardians.

The Wingspread recommendations led to a comprehensive study of guardianship monitoring undertaken by the ABA Commission on the Mentally Disabled, the ABA Commission on Legal Problems of the Elderly, and the State Justice Institute (SJI).[111] In addition to the study, SJI funded projects on guardianship monitoring, pioneering the use of volunteers to be the "eyes and ears" of the court in guardianship cases, and the use of a national model of judicial review of guardian performance.[112] The National Probate Court Standards, which were published in 1993, incorporated some of the recommendations and the lessons learned from subsequent studies.[113] As a result, state reform efforts that were ignited by the 1987 AP story were informed not only by the available models from the ABA's model statute and/or

the 1982 UGPPA, but also by the Wingspread recommendations and subsequent reform initiatives. Consequently, throughout the late 1980s and early 1990s, state statutes were revised to include improved due process procedures, processes for determinations of capacity based on functional assessments rather than merely on diagnoses, and greater accountability, including reporting requirements and court monitoring practices. Finally, in 1997, the UGPPA was revised to emphasize limited guardianship, reporting requirements, and monitoring.[114] Many states also established a preference for limited guardianship in their statutes and required courts to find that there was no appropriate less restrictive alternative to guardianship before a guardian could be appointed.[115]

"I think we got the laws in pretty good shape, [but] it is less clear that these reform efforts were able to supplant deeply entrenched practices of guardianship law."

—Interviewee

These reform activities have been described as "a headlong rush of statutes, handbooks, training videos, legal and judicial curricula, and studies of public guardianship and court oversight."[116]

Early 2000s: Second Wave of Guardianship Reform

These early reform efforts clearly led to vast improvements in the statutory framework of

guardianship, but it remained apparent in the decades that followed that guardianship is a much better idea in theory than in practice. As one person interviewed for this report noted, "I think we got the laws in pretty good shape" but, she added, "it is less clear that these reform efforts were able to supplant deeply entrenched practices of guardianship law." Unfortunately, as we'll examine in later chapters, there continues to be a gap between the lofty goals of the reforms codified in statute and the way that guardianship plays out in individual states, jurisdictions, and courtrooms across the country.

Realizing that there was more work to be done, in 2001, more than 80 national experts in guardianship law and practice gathered at Stetson College of Law in Florida for a conference that was dubbed "Wingspan," in homage to the original "Wingspread" conference held more than a decade before. The conferees at Wingspan assessed the strengths and weaknesses of implementation of the past reforms and, at the close of the conference, made 68 additional recommendations for reform.[117] In addition to the recommendations, the conference gave rise to a special edition of the Stetson Law Review that included articles prepared for the conference that largely examined whether the Wingspread reforms had been adopted and whether they had been transformative; and suggested avenues for better implementation.[118]

Overall, the Wingspan conference was less influential than its predecessor, offering mostly refinements to the original recommendations. However, it did aim to bring the still widely disparate state laws into greater alignment and addressed a concern that had largely been ignored by the Wingspread conferees: interstate jurisdictional issues. The first recommendation to come out of Wingspan encouraged "the development of procedures to resolve interstate jurisdiction controversies over which state's court has jurisdiction to appoint a guardian."[119] Additionally, the recommendation encouraged states to develop procedures to facilitate the transfer of existing guardianship cases among jurisdictions. Largely based on this recommendation, the Uniform Law commission drafted the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act, which has since been enacted in all but five states.[120] However, if "the challenge of Wingspan is the implementation of its recommendations,"[121] as A. Frank Johns and Charles Sabatino wrote in the introduction to the special edition of the *Stetson Law Review* devoted to papers emerging from Wingspan, then the success of Wingspan has been mixed.

In many ways, we are in a "third wave" of guardianship reform right now, ushered in by the demographic tsunami of the aging baby-boom generation . . .

Present Day: Third Wave of Guardianship Reform

In many ways, we are in a "third wave" of guardianship reform right now, ushered in by the demographic tsunami of the aging baby-boom generation whose members are entering the age when they might be at risk of guardianship due to declining health, dementia, and acquired disabilities. Indeed, those over age 85 are already the fastest growing demographic—and that

does not even include the baby-boom generation members who are just now entering their 70s.[122] The sheer number of people who are living longer will put a strain on all the systems that we have traditionally used to support people as they advance in age, including guardianship. Additionally, the famously independent baby-boom generation will not be likely to accept traditionally paternalistic models of support that undermine their independence and self-determination.

The Third National Guardianship Summit in 2012 built on the work of the two previous conferences, Wingspan and Wingspread. This summit focused on post-appointment guardian performance, including developing person-centered plans for the individual subject to guardianship; meeting responsibilities to the court, including reporting and facilitating the court's monitoring of guardianships; and finally, involving the person in decision making and working toward restoring capacity whenever possible. The summit did not abandon the previous "wings" theme altogether; rather, the Working Interdisciplinary Networks of Guardianship Stakeholders, or "WINGS" groups, grew out of the summit. In 2013, the National Guardianship Network selected New York, Oregon, Texas, and Utah to pilot these WINGS groups, and each brought together stakeholders in each state to examine the state's guardianship system and make recommendations. Six additional states were subsequently provided with small amounts of funding to bring together stakeholders, and an additional six states created similar groups that were unfunded for eighteen total groups. Finally, in 2016, the ABA Commission on Law and Aging, with the National Center for State Courts, received an Elder Justice Innovation Grant from the U.S. Administration on Community Living (ACL) to establish, expand, and enhance state WINGS groups. This grant provides funding for WINGS projects in eight states.[123]

The focus of WINGS groups in individual states varies, but in general the goal of the project is to ". . . improve the ability of state and local guardianship systems to develop protections less restrictive than guardianship, advance guardianship reforms, and address abuse."[124] The work of individual WINGS groups will be discussed later in the report. Several of the groups have undertaken studies of their state guardianship systems that have added to what we know about guardianship, which will be the focus of Chapter 4, and some have begun developing tangible solutions to some of the most difficult issues in guardianship, including advancements in the data collection, monitoring, and development of viable less-restrictive alternatives to guardianship. The WINGS groups are an important model for reform because they bring together local stakeholders from a variety of perspectives and create a nationwide network that allows for the effective sharing of information and ideas, allowing states to drive reforms supported in part by federal funding.

[I]n general the goal of [WINGS groups] is to ". . . improve the ability of state and local guardianship systems to develop protections less restrictive than guardianship, advance guardianship reforms, and address abuse."

In addition to the Third National Guardianship Summit and the WINGS groups, as indicated in Chapter 2, the adoption of the United Nations Convention on the Rights of Persons with

Disabilities in 2006 has also been an important driver of guardianship reform worldwide in countries outside the United States. Article 12 of the CRPD provides that people with disabilities are entitled to "equal protection before the law" and requires states to recognize "that [people] with disabilities enjoy legal capacity on an equal basis with others in all aspects of life" and to "take appropriate measures to provide access by [people] with disabilities to the support they may require in exercising their legal capacity."[125] The implications of Article 12 mandates for guardianship law and the practice of substituting the decisions of a guardian for that of a person with a disability are staggering—particularly given the CRPD committee has taken the consistent and unanimous view that all forms of guardianship violate this article. As one scholar noted, "Article 12 is arguably the most controversial provision in the Convention. It is also arguably the most important and 'revolutionary.'"[126]

One interviewee described supported decision making as "what really good family and friends do. It's having conversations with each other about needs and wants and coming to a decision with their help when needed."

The Dawn of Supported Decision Making

The CRPD has led to a sea of change in guardianship laws of signatory countries, and, philosophically, it has impacted the way that guardianship is understood in the United States even though it has not been ratified by the United States as Dr. Robert Dinerstein summarized: "[A] contextual reading of the Article and its provenance certainly calls into question the continued viability of surrogate decision-making arrangements such as guardianship." Important as some of the past reforms to guardianship may have been:

> . . . they still accept the predominance of a legal regime that locates decision making in the surrogate or guardian and not in the individual being assisted. In contrast, supported decision making, which Article 12 embraces, retains the individual as the primary decision maker, while recognizing that the [person] with a disability may need some assistance—and perhaps a great deal of it—in making and communicating a decision.[127]

This rejection of surrogate decision making in favor of supported decision making is a more fundamental paradigm shift than the reforms that began in the 1980s in that it does not simply improve the process for establishing guardianship in the hope of ensuring more accurate determinations of incapacity, nor does it simply insist that guardians ask for input from the individual subject to guardianship on important matters, or refrain from abusing, exploiting or neglecting them. Rather, supported decision making "aims to retain the individual as the primary decision maker but recognizes that an individual's autonomy can be expressed in multiple ways, and that autonomy itself need not be inconsistent with having individuals in one's life to provide support, guidance and assistance to a greater or lesser degree, so long as it is at the individual's choosing."[128] One interviewee

described supported decision making as "what really good family and friends do. It's having conversations with each other about needs and wants and coming to a decision with their help when needed."

This paradigm shift toward supported decision making was demonstrated in 2014 at the 3rd World Congress on adult guardianship, which was held in Washington, D.C. More than 360 participants from 22 countries on six continents presented on a variety of topics, but one consistent theme was how countries were attempting to align their guardianship statutes and practices with the Article 12 mandate. Many of the delegations that presented at the conference demonstrated how their countries have begun to conceptualize and, in some cases, implement supported decision making as a legal alternative to guardianship. Among others, the governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring adopting supported decision making.[129]

[T]he governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring adopting supported decision making.

Supported decision making has become a very important part of the conversation around guardianship reform in the United States as well. Supported decision making is not only a concept driven by the CRPD, but it is also seen as a way to answer a fundamental challenge raised by Professor Leslie Salzman, who argued in a 2010 law review article that substituted decision making (i.e., guardianship) is antithetical to the integration mandate outlined in the Supreme Court's *Olmstead* decision and subsequent case law. She argues ". . . that by limiting an individual's right to make his or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the [ADA's] mandate to provide services in the most integrated and least restrictive manner."[130] An extensive examination of supported decision making follows in Chapter 8.

" . . . [B]y limiting an individual's right to make his or her own decisions, guardianship marginalizes the individual and often imposes a form of segregation that is not only bad policy, but also violates the [ADA's] mandate to provide services in the most integrated and least restrictive manner."

Revising the UGPPA

The UGPPA was approved by the Uniform Law Commission in 1982, amended in 1989, and revised in 1997. Nearly 20 states have adopted some version of the UGPPA.[131] However, even where it has not been enacted, the UGPPA has had a profound influence on the development of U.S. guardianship law.[132] In 2014, the Uniform Law Commission began the process

of revising the UGPPA in order to implement the standards and recommendations of the Third National Guardianship Summit. The Uniform Law Commission approved the revised version of the model law, now called the UGCOPAA, on July 19, 2017. New Mexico is the first state to move to adopt the model legislation, which has passed in the state Senate.

While the UGCOPAA includes a number of important changes, perhaps the most crucial reform is that it

> recognizes the role of, and encourages the use of, less restrictive alternatives, including supported decision-making and single-issue court orders instead of guardianship and conservatorship. To this end, the revised Act provides that neither guardianship nor conservatorship are appropriate where the person's needs could be met with technological assistance or decision-making support.[133]

The UGCOPAA focuses on the need to limit the use of guardianship and create alternatives that maximize the self-determination of those who may need decision making assistance . . .

The UGCOPAA makes several other changes to the model guardianship statute, including:

- replaces the terms *incapacitated person* and *ward* with *individual subject to* either guardianship or conservatorship;
- strengthens notice requirement and prohibits waivers of notice;
- raises the standard for excusing the absence of the individual who is allegedly incapacitated from "good cause" to "clear and convincing" evidence of limited circumstances that excuse the individual from attending;
- requires capacity determinations to be based more on a functional rather than medical model;
- increases use of "visitors" and professional evaluators to make capacity determinations;
- requires a court to state why a full guardianship is imposed rather than a limited guardianship;
- requires the court order to state whether rights to marry and vote are retained;
- requires individuals subject to guardianship and other interested parties to receive a statement of rights when the guardianship is established;
- imposes additional requirements before a guardian may alter living situations
- requires the guardian to frequently visit the person;
- specifies when the court is required to hold a hearing to determine if a modification of the guardianship is needed, particularly upon receipt of communication by the individual or another interested party, such as a family member;
- requires courts to terminate guardianships if the petitioner establishes a prima facie case for termination, unless the legal basis for guardianship is met; and
- creates a process for a time-limited protective arrangement (e.g., to authorize a medical procedure or the sale of property) instead of guardianship.

The UGCOPAA focuses on the need to limit the use of guardianship and create alternatives that maximize the self-determination of those who may need decision making assistance, but to also create mechanisms that enable those individuals to receive the right amount of assistance when they need it. Additionally, the model statute attempts to provide clarity and accountability in some areas that the previous statute had left within the realm of judicial discretion. Like the UGGPA before it, the result of this work is a groundbreaking document with a great deal of potential to transform guardianship—but, also like the previous iteration, its influence will depend on the willingness of states to adopt it and judges and lawyers to follow it both in letter and spirit.

Jenny Hatch: The Face of the Third Wave of Reform

Model statutes can change laws, but it often takes a personal story to change hearts and minds. Few guardianship cases have received as much national attention as the Jenny Hatch case, even before the four-page glossy feature on her case in the February 17, 2014, edition of *People Magazine*, as well as coverage on CBS News and in the *Washington Post*.[134]

Jenny Hatch

Jenny Hatch is an adult woman with Down syndrome living in Virginia who, before an unfortunate bike accident in 2012, lived a happy, productive, and independent life; was active in her community; and got by with minimal supports. After having surgery on her spine following the accident, Ms. Hatch moved in with her employers from the thrift store where she worked. Her parents filed a guardianship action, and she was placed under temporary guardianship and forced to move into a group home pending the outcome. Ms. Hatch hated the group home, saying that she felt like a prisoner.[135] Ms. Hatch's lawyers presented evidence that permanent guardianship was not necessary, as she was capable of managing her own life with supported decision making support from people she chose.[136] The judge agreed in part, ruling that Ms. Hatch's guardianship would be limited in scope ("medical and safety decisions") and in time (one year), and that it would be with the

(continued)

Jenny Hatch: The Face of the Third Wave of Reform, *continued*

guardians of her choice. The judge also recognized the role of supported decision making, both within the one-year guardianship and after it terminated. The judge's order also freed Ms. Hatch from the group home, allowing her to live in the community with her friends.

Since the ruling, Ms. Hatch has returned to live with her friends who own the thrift store where she worked and has traveled across the country, speaking at conferences and events about her experiences and the value of supported decision making.[137] She has become an eloquent spokesperson on both the danger of overly restrictive guardianship and the need for alternatives such as supported decision making. From a legal standpoint, her case is significant because it, along with *In Re Guardianship of Dameris L,* is one of the earliest cases to recognize supported decision making as a viable alternative to guardianship, and her advocacy has provided attorneys for similarly situated clients with a powerful example of the value of this alternative. As Professor Jasmine Harris of the UC Davis School of Law wrote, "[t]he Hatch victory also resonates more broadly as a common rally point and mirror of the lived experiences of many other people with disabilities who are subject to the same presumptions of incompetence and incapacity."[138]

In conclusion, this "third wave" of guardianship reform has been fundamentally different than the earlier reform efforts, not only because it represents a fundamental shift from the surrogate decision making framework of guardianship—which previous efforts sought to limit but not fundamentally question—but also because supported decision making has more of the earmarks of a popular movement than some of the previous reform efforts. Not only are activists, scholars, lawyers, advocates, and others advocating to bring about systemic change to the guardianship system, but individuals like Ms. Hatch are also advocating for their right to self-determined lives and demanding that the legal system develop and recognize alternatives to guardianship, such as supported decision making. It is the experiences of Ms. Hatch, litigants who come after her, and participants in programs such as supported decision making pilot projects in Massachusetts,[139] Texas,[140] and New York[141] that will shape guardianship reform in the future. Texas recently became the first state to recognize supported decision making in statute and to require courts to consider it before guardianship.[142] Hopefully, this grassroots involvement will help circumvent some of the pitfalls of earlier reforms, which were often exciting in theory but disappointing in practice.

Chapter 4: The Current Guardianship System in America

Although there is some disagreement about why, there is a general consensus that the guardianship system is not in much better shape than it was in 1987, despite decades of reform efforts. Chapter 4 will describe the current state of guardianship in broad strokes and will identify issues for more detailed examination in later chapters.

The Current System Lacks Data

The lack of data on who is under guardianship or what happens to adults under guardianship is a constant source of frustration for anyone attempting to understand guardianship, much less those urging policymakers that there is an immediate need for resources to address problems arising from it. Erica Wood and Sally Balch Hurme, both of whom have studied guardianship for decades and worked tirelessly to improve it, note in their introduction to the special symposium issue of the Utah Law Review reporting out the results from the 3rd National Guardianship Summit that:

> [w]e as a nation 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.[143]

"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."

Data on the Number of People Subject to Guardianship

Brenda Uekert, Principal Court Research Consultant for the National Center for State Courts (NCSC), has probably spent more time "crunching the numbers" to develop a statistical picture of guardianship than any other researcher. After decades of studying guardianship, she estimates that there are 1.3 million active adult guardianship or conservatorship cases and that courts oversee at least $50 billion of assets under adult conservatorships nationally.[144] This estimate is based on the handful of states that do track and report reasonably reliable data on guardianships; however, Dr. Uekert notes that there is wide variation among the states and it is difficult to extrapolate what we know from a few states to the country as a whole. Additionally, most states do not adequately sort data in a way that allows

researchers to draw accurate conclusions from the available data. Dr. Uekert observes:

> . . . few states are able to report complete statewide adult-guardianship caseload data, because these cases are counted in a generic probate case type or otherwise blended into civil caseload statistics. A number of states cannot distinguish adult guardianships from adult conservatorships as distinct case types. Other states include both juvenile and adult guardianships in a single "guardianship" case type.[145]

It goes without saying that if we do not know how many guardianships there are, we also cannot say for sure whether guardianship is a growing trend or if its popularity is waning, making it difficult to urge policymakers to address the problems in guardianship, since it is difficult to prove that the problems are, in fact, growing.

. . . [F]ew states are able to report complete statewide adult-guardianship caseload data, because these cases are counted in a generic probate case type or otherwise blended into civil caseload statistics.

Data on the Number of Filings

Despite the lack of reliable data, there is some evidence that suggests that the number of adults subject to guardianship has been rising. In 2009, the National Center for State Courts asked 187 respondents to respond to a survey distributed through association listservs such as the National College of Probate Judges, the National Association for Court Management, and the American Judges Association. The goal of the study was to ascertain how guardianship filings had changed over the previous three years. Most respondents said that filings had stayed the same; however, 37 percent noted an increase in petitioners seeking guardianship over a person who allegedly lacked capacity and only 4.28 percent noted a decrease. This means that the number of new petitions for guardianship is either staying the same or rising, but almost certainly not decreasing. Similarly, a significant minority of 43 percent noted an increase in the number of open, ongoing guardianships over the past three years, another indication that the number of guardianships may be on the rise.[146]

However great or small the increase may have been in recent years, looking to the future, it is very likely that the need for decision making assistance will grow in the years to come:

> The need for guardianship and other surrogates will grow as the population ages, and as the prevalence of Alzheimer's disease, the number of "old old," and the number of [people] with intellectual disabilities, mental illness, and traumatic brain injury all increase.[147]

After all, the anticipated rise in the senior population is well-documented and fueling concerns about demands on the already overstretched direct-care workforce.[148] It is also possible that, even though their numbers are likely to be more stable over time, more young adults with disabilities are being made subject to guardianship as states rebalance their systems in favor of community options. It's possible that guardianship among this population is more prevalent now because parents of

adults with disabilities see guardianship as a way to continue to manage care and services in the community, whereas a generation ago those services would have been provided in the closed system of an institution. However, without better data that could track the number of guardianships over time and describe at least the basic characteristics of individuals subject to guardianship, there is no way to say definitively what the trends in guardianship are. This is problematic because "[t]he starting point of any major reform is an accurate picture of the policy in need of reform; in this case, that means at a minimum that states are able to count the number of incoming and outgoing adult guardianships in the state courts."[149] Unfortunately, in the case of guardianship, that is something we cannot currently do. Despite the recent interest in the topic that has given rise to a number of the studies reported here, a comprehensive picture of guardianship trends is unlikely to become clear unless states begin regularly gathering and reporting accurate and comparable data.

"The starting point of any major reform is an accurate picture of the policy in need of reform; in this case, that means at a minimum that states are able to count the number of incoming and outgoing adult guardianships in the state courts."

What Is Known from Limited Data

Without reliable data, it's difficult to describe the extent of the problems in guardianship or to quantify the number of good or bad outcomes. However, continual and pervasive anecdotal data and what limited quantifiable data does exist strongly suggest there are very serious problems. Several notable studies have been done that attempt to ascertain whether guardianships are working as intended and to identify problem areas. Additionally, state task forces, including those funded as "WINGS" projects, have examined state guardianship programs, and national and local press reports continue to highlight some of the ongoing problems in guardianship. Generally speaking, these sources all point to problems that involve a lack of information about alternatives, insufficient due process when a guardianship arises, a failure of courts to monitor guardianships and abuse, neglect or exploitation by guardians and conservators, and a lack of an appropriate response to the concerns of families or individuals subject to guardianship. Although each of these issues will be addressed in greater depth later in the report, a brief review of available information will help characterize and summarize the current state of guardianships today.

2014 SSA Representative Payee Report

In 2014, the Social Security Administration (SSA) conducted research in response to repeated calls to do a better job coordinating its "representative payee" program with state guardianship systems. In order to do that, SSA asked the Administrative Conference of the United States (ACUS), which then worked with NCSC, to study current guardianship laws and practices. ACUS researched state guardianship laws and court practices, conducted a survey regarding court practices in guardianship, and interviewed nine state organizations or entities related to adult

protective services or foster care to evaluate their practices with respect to guardianship. The findings of the study were interesting and informative, although the authors caution that it is not based on a representative sample, making it difficult to say with certainty whether these findings reflect guardianship nationally. The major findings of the study include the following:

- Approximately 75 percent of guardians were friends, family, or acquaintances as opposed to professional or public guardians.
- 60 percent of court respondents in the survey do not review the credit histories of potential guardians, and about 4 in 10 do not conduct criminal background checks.
- 47 percent of the courts in the survey inquired about a potential guardian's representative payee status with respect to the individual for whom they are guardian.
- 75 percent of the courts in the survey required inventory filings at or near the time of the appointment of guardians of the property in all cases, and about two-thirds of respondents indicated annual accounts are required as well.
- 75 percent of all respondents indicated that at least some of the financial accounting forms are subject to audits or a similar type of evaluation, usually conducted by court staff or judges themselves. It's unclear how thorough these audits are.
- Approximately 66 percent of respondents indicated that they currently use some kind of electronic case management database for guardianship cases, and a small additional number of respondents said they expected to be using one by 2017.
- Approximately 66 percent of court respondents indicated that the court had sanctioned a guardian for failure to fulfill their obligations, misconduct, or serious malfeasance within the past three years. In these cases, the court removed the guardian or issued an order requiring the guardian to show cause why they had failed in their duty or cited the guardian for contempt for failing to comply with the statute or with a court order. However, in most cases, the action taken was only noted within the guardianship file.[150]

> *[T]he fact that courts are not able to definitively report the number of open guardianship cases . . . is indicative of what is widely acknowledged to be incredibly lax monitoring . . ., despite statutory reforms requiring guardians to provide courts with annual reports regarding the welfare of the individual and accountings detailing how their resources are being spent.*

2010 Study of the National Center for State Courts' Center for Elders and the Courts

A 2010 study conducted by the National Center for State Courts' Center for Elders and the Courts (CEC) on behalf of the Conference of Chief Justices/Conference of State Court Administrators (CCJ/COSC) Joint Task Force on

Elders and the Courts, examined the availability and correctness of adult guardianship data; the adequacy and training of guardians; and promising practices for guardian recruitment, retention, and training.[151] The study's authors again warned that results are not nationally representative. In addition to noting the lack of reliable data and that the number of guardianships seemed to be on the rise as noted previously, their major findings included the following:

- Securing and retaining family and friends to act in the capacity of guardian is problematic for half of the reporting jurisdictions.
- There is considerable need for additional public and private professional guardians. The greatest need for training is for family and friends serving as guardians.
- Guardianship monitoring efforts by the courts are generally inadequate.[152]

State Data

Nationwide studies are one way to try to capture the current state of guardianships. Another way is to look at available data from selected states. Since each guardianship system is unique, it can be difficult to compare state systems. However, the WINGS effort has led to a number of states taking a close look at their guardianship systems to identify areas for improvement.

Some brief examples of findings from several of these studies follow:

New York

A recent study by the Brookdale Center for Healthy Aging at Hunter College reviewed 2,414 Article 81 cases files across New York State. Because New York has a separate guardianship statute for people with ID/DD, cases involving people with ID/DD were not included in this data. Of the cases opened, they found that the court appointed a guardian 68 percent of the time, or 1,636 cases. Further, they found that 68 percent of the individuals subject to guardianship were female; 59 percent were over age 65; and dementia was the reason for incapacity in 41 percent of cases, with psychiatric disability as the reason in 20 percent of cases.[153] In 43 percent of cases, a family member or friend petitioned to be guardian, and in those cases, a family member or friend was appointed in 86 percent of cases.

Texas

The Texas State Office of Court Administration reviewed a total of 165 guardianship cases filed in 2013 in 14 selected counties that were a mix of semiurban and rural jurisdictions. Of the individuals subject to guardianship, they found a fairly even division between male and female, with 55 percent being male. Seventy-four percent lived at home either in their own home or, in some cases, the family home, in the community when the petition for guardianship was filed, with 21 percent living in a long-term facility such as a nursing home. Fifty-one percent of the cases filed involved an individual who was turning 18. In terms of the characteristics of the guardian, 85 percent were family members, 10 percent were public guardians or Department of Aging and Disability Services (DADS) cases, and 6 percent involved the appointment of a private professional guardian.[154]

Indiana

The Indiana Adult Guardianship State Task Force is a multidisciplinary workgroup convened to examine the adult guardianship system in

Indiana. In a comprehensive 2012 report, they found that there are approximately 7,000 people who are subject to guardianship in Indiana. Of the new guardianship cases filed in a selected sample of 14 counties, 25.8 percent involved an allegation that the AIP had dementia; 22 percent involved a person who had cognitive or intellectual disabilities; 10.5 percent involved a person with severe mental illness; 5.4 percent were stroke related; 5 percent were related to an acquired head injury; 1.4 percent involved chronic intoxication; and 1.4 percent involved other conditions associated with old age. An additional 15.1 percent of the cases were classified as "other" and in the remaining 13.4 percent of the cases no reason for the incapacity was specified in the file.[155]

What the Lack of Data Means

Not only is the lack of robust data in guardianships troubling because it leaves us without an accurate picture we can use to craft effective policy, it is actually indicative of a larger problem. Courts are supposed to be monitoring guardianships in order to protect individuals subject to guardianship from abuse, neglect, and exploitation at the hands of their guardians and to make sure that guardians continue only as are necessary. However, the fact that courts are not able to definitively report the number of open guardianship cases at a given point in time is indicative of what is widely acknowledged to be incredibly lax monitoring on their part, despite statutory reforms requiring guardians to provide courts with annual reports regarding the welfare of the individual and accountings detailing how their resources are being spent.

The National Center for State Courts' (NCSC) Conservatorship Accountability Project is working with several grantee states on developing accounting and tracking processes and safeguards that will not only protect vulnerable adults from financial exploitation, but also provide a template for streamlined and compatible case management platforms that would make it relatively easy to collect and compare data on a statewide and even nationwide basis.[156] We will examine the deficiencies in monitoring practices that leave individuals subject to guardianship vulnerable to abuse, neglect, and exploitation in more depth in Chapter 7, as well as highlight some promising practices.

Does Guardianship Prevent Abuse or Lead to It?

U.S. Government Accountability Office (GAO) Reports on Guardianship

Particularly in the past decade, there is renewed concern regarding elder abuse and whether guardianship is an effective tool against potential abusers or a tool that gives potential abusers carte blanche to commit acts of abuse. GAO has twice been asked to review whether abusive practices by guardians are widespread, releasing reports in 2010 and another in 2016. The 2016 report noted, "[t]he extent of elder abuse by guardians nationally is unknown due to limited data on the numbers of guardians serving older adults, older adults in guardianships, and cases of elder abuse by a guardian."[157] However, the 2010 GAO report ". . . identified hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010."[158] These included cases ranging from financial neglect where bills simply went unpaid, leading to foreclosure; cars being repossessed; electricity being shut off; and credit being

destroyed; to cases where guardians were able to siphon millions from individuals subject to guardianship (both senior and young adults); to at least one case where the guardian falsely claimed the individual subject to guardianship had terminal cancer and moved her into hospice care where she later died from the effects of morphine.[159]

Notably, both GAO reports are careful to assert that these are nongeneralizable examples. Nonetheless, while the examples of abuse GAO uncovered are only illustrative, it is apparent from the totality of available evidence regarding guardianship practices, that courts are not currently able to safeguard individuals against abuse, neglect, and exploitation committed by guardians. While it cannot be said that the findings of the GAO report demonstrate that abuse is occurring in the majority of guardianship cases, it would also be a mistake to assume that GAO only found and reported on the outliers. The GAO reports raised significant red flags for Congress, which passed the Elder Abuse Prevention and Prosecution Act of 2017.[160] The Act addresses elder abuse beyond guardianships, but specifically authorizes grants issued under the Elder Justice Act to assess guardianship and conservatorship proceedings and to implement changes deemed necessary based on these assessments, including mandating background checks for guardians, implementing systems to enable more consistent filing of annual accountings, and reports as well as regular auditing of this information.

[T]he 2010 GAO report ". . . identified hundreds of allegations of physical abuse, neglect and financial exploitation by guardians in 45 states and the District of Columbia between 1990 and 2010."

[W]hile the examples of abuse . . . are illustrative and not generalizable, it is apparent . . . that courts are not currently able to safeguard individuals against abuse, neglect, and exploitation committed by guardians.

Those who find the status quo of guardianship acceptable often view the existing system as one which provides needed protection to people who are vulnerable to abuse or exploitation. One professional guardian interviewed for this report explained, "[F]or somebody who is financially exploited, oftentimes the guardianship is the only way to protect them." While this concern is valid, so is the concern that guardianship itself may lead to negative or abusive outcomes. The Elder Abuse Prevention and Prosecution Act is an important step toward getting a handle on this problem, once deemed local, that has the potential to become a national crisis as the population ages.

Investigative Reporting

Investigative reporters have also taken up this question, and the results have been disconcerting. In July 2016, the *Texas Observer* reported on the Texas guardianship system in a report entitled, *Who Guards the Guardians,* very much painting a picture of a system in crisis. The report details the case of a professional guardian

who was accused of charging individuals for whom he served as guardian large percentages of their income, failing to visit them in their nursing homes and selling off their homes and possessions, often without their knowledge, and pocketing a share of the proceeds for himself. According to the report, this went on for years before he lost his license to be a professional guardian. The judge who oversaw all 1,425 guardianship cases in the county finally appointed the wife of the discredited professional guardian to many of his former cases. She was later fined $25,000 total for 51 additional legal violations.[161]

Another recent case in Nevada has garnered considerable media attention. In March 2017, a professional guardian was indicted as the alleged ring-leader of a criminal syndicate. She and three associates were charged with more than 200 felony counts in a scheme to bilk clients with disabilities and senior clients out of their life savings.[162]

Finally, a compelling article appeared in the *New Yorker* in October 2017 that reviewed several cases where a professional guardian had seemed to take over the lives of senior individuals, removed them from their homes, separated them from loved ones, and charged them what seemed to be exorbitant amounts for guardianship services they had never asked for or wanted.[163]

Although the previously mentioned accounts may lead one to conclude that it is only professional guardians who are problematic and that family guardians are less likely to abuse individuals subject to guardianship, there exists at least some data to the contrary.

A recent Minnesota study found that of 31 cases of financial exploitation, 24 involved a family member. In fact, ". . . closer analysis of family relationships showed that the greatest number of victims were exploited by their own children, followed by siblings and then other close relatives."[164] Professional guardians are frequently called in to manage a person's affairs when family members are either feuding with each other over the individual who is allegedly incapacitated or when the person has been abused, neglected, or exploited by a family member. We will explore these issues further in Chapter 7.

A recent Minnesota study found that of 31 cases of financial exploitation, 24 involved a family member.

Chapter 5: Capacity and the Role of "Experts" in Guardianship Proceedings

Introduction

As explored in Chapter 1, there was a time when personal characteristics such as race, gender, and having a label of disability were enough to deny an individual the basic rights of citizenship. Historically, determining that a person needed a guardian or involuntary commitment to an asylum due to "insanity" was predicated on very amorphous standards. For example, in 1742, the Rhode Island general assembly codified "[a]n act empowering several town councils of this colony to have the care and oversight of all persons who are delirious, distracted, or non-compos mentis, and their estates."[165] In 1822, the legislature updated the law and replaced "delirious and distracted" with what at the time was considered more scientific designations of "idiot" and "lunatic."[166] Despite the sheen of science being added to state guardianship statutes across the country in the early 19th century, well into the 20th century, not even physicians' reports were deemed essential to determining capacity ("competency"), and socially inappropriate behavior, forgetfulness, or bewilderment could form the basis of a judicial label of insanity. Judges made similarly unscientific determinations of incompetence for reasons of age, intellectual disability, and even alcoholism.[167]

Today, at least in theory, every individual who is 18 or older:

> is presumed to possess the requisite level of capacity. All adult individuals are presumptively able to avail themselves of legal protections, to make legally binding decisions, and to be held responsible for their actions and decisions . . . Today, lack of capacity must be proven affirmatively, often by clear and convincing evidence.[168]

Present day determinations of incapacity are usually based on a combination of medical and functional criteria, and courts rely heavily on the input of physicians and other professionals who purportedly have expertise in determining capacity.

Present day determinations of incapacity are usually based on a combination of medical and functional criteria, and courts rely heavily on the input of physicians and other professionals who purportedly have expertise in determining capacity.[169]

The guardianship reforms of the past 30 years have largely focused on limiting who is subject to guardianship, limiting guardianship to specific areas in which the individual lacks capacity, and statutorily mandating strict due process procedures that should lead to fair and thoroughly tested outcomes that meet a high standard of proof. Accordingly, many statutes now specifically require medical documentation and often an independent evaluation by a physician who advises the court whether, in his or her professional opinion, the individual has capacity. However, some of the same reformers who had hoped to improve the quality, accuracy, and fairness of capacity evaluations to make sure that only individuals who truly lack capacity are subject to guardianship are beginning to consider the possibility that capacity is problematic and rooted more in the ideological construct of liberal autonomy and lacks a verifiable or scientific basis.[170] In this chapter, we will explore the legal and philosophical bases of "incapacity" as justification for legal interference with individual autonomy.[171] We will also examine how incapacity determinations are made and discuss whether fair and consistent determinations are possible, either under the current systems or after further reform.

Moving Away from the "Reasonable Man" Standard of Capacity

Philosophical Origins

As discussed briefly earlier in this report, individual autonomy is a cornerstone of western philosophy and is particularly important in the American constitutional system. Influential German philosopher Immanuel Kant developed this philosophy, which was later expanded upon by English philosopher John Stuart Mill. While a deep investigation of the ideas of these influential philosophers is well beyond the scope of this report, it is worth noting that the basis for our cultural and legal assumptions about autonomy and liberty, which ultimately give rise to the legal concept of "capacity," are as much philosophical as they are medical. In Kant's view, the ability to decide how to live one's life is the most basic autonomy right.[172] These ideas heavily influenced the founding fathers, as indicated by the Declaration of Independence assertion that "all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the Pursuit of Happiness."[173]

In the justice system, when something bad happens as a result of an individual's actions, their legal responsibility often depends whether and to what extent they engaged in a rational thought process leading to the consequences. Specifically, they may be described as having acted intentionally, recklessly, or negligently.

In particular, in determining whether a particular action was negligent, courts try to determine what the "reasonable man" would have done under the circumstances. The reasonable man has been described as someone whose every behavior commands admiration:

> . . . He is one who invariably looks where he is going, and is careful to examine the immediate foreground before he executes a leap or a bound; . . . who believes no gossip, nor repeats it, without firm basis for believing it to be true; . . . who in the way of business looks only for that narrow margin of profit which twelve men such as himself would reckon to be 'fair' . . . ; who

> uses nothing except in moderation, and . . . is meditating only on the golden mean. Devoid, in short, of any human weakness, with not one single saving vice, sans prejudice, procrastination, ill-nature, avarice, and absence of mind, . . . this excellent but odious character stands like a monument in our Courts of Justice, vainly appealing to his fellow citizens to order their lives after his own example.[174]

The reasonable man, when he is being an economic actor, is often fancifully referred to as *homo economicus*, in that he is consistently rational and narrowly self-interested. Mill described the "economic man" as "an arbitrary definition of man, as a being who inevitably does that by which he may obtain the greatest amount of necessaries, conveniences, and luxuries, with the smallest quantity of labour and physical self-denial with which they can be obtained."[175] These concepts of who we are as human beings, how we make decisions, and why we are possessed of the right to make decisions at all are critical concepts that give rise to the very idea that a person can be accurately described as having or lacking capacity; even as our understanding of "capacity" as a concept has evolved over time and become more complex and has expanded to include people that were not always given credit as capable of rational thought.

Behavioral Economics

The work of Nobel Prize winner psychologist Daniel Kahneman, the late psychologist Amos Twersky, and 2017 Nobel Prize–winning economist Richard Thaler—known as the founders of "behavioral economics"—have revolutionized our understanding of human decision making, revealing a process that is very different from the "rational utility maximization presumed by neoclassical economics."[176] The field of behavioral economics has largely proved that the majority of our decisions are not the result of careful consideration. In fact, when Dr. Thaler was asked how he intended to spend his Nobel prize money, he quipped, "I will try to spend it as irrationally as possible."[177] Behavioral economics shows that an individual's behavior in making choices departs from exclusive rational choice behavior because of instances of failures to act in one's own interests, which can be said to be irrational behavior.

Behavioral economics not only calls into question whether humans act rationally with respect to economics, but it undermines the fundamental belief that our decisions are based in reason. Yet, the guardianship paradigm assumes that people are entitled to rights in proportion to their ability to exercise the reason necessary to make autonomous decisions. It seems basically unjust to take away the right of a person with disabilities to make their own decisions when there is growing evidence that no one—including a court-appointed guardian—makes decisions on a rational basis.

Behavioral economics . . . undermines the fundamental belief that our decisions are based in reason. Yet, the guardianship paradigm assumes that people are entitled to rights in proportion to their ability to exercise the reason necessary to make autonomous decisions.

Capacity Determinations

Who Decides Capacity?

Because there is a legal presumption that individuals who have reached the "age of majority" have capacity, it is generally not until a judge determines that one lacks capacity that a person can be said to be incapacitated. Although a person may have a particular diagnosis and seem to those around him to lack the ability to make or communicate a decision, he is still entitled to exercise his fundamental rights in a variety of ways. However, doctors, landlords, bankers, and others may nonetheless refuse to treat, rent to, or conduct business with a person they perceive to lack capacity, for fear that the person is not able to understand what is happening, which could ultimately expose them to liability. This is especially true of doctors and some other professions that require gaining one's "informed consent" before acting (e.g., medical treatment). However, having a doctor refuse to treat a person based on his or her assessment that an individual is not capable of giving informed consent to a procedure has limited legal consequences for that individual; the person is free to keep looking for a doctor who will allow them to consent to the procedure.

In many states, although not all, it is only when a judge finds that there is "clear and convincing evidence" that the person lacks

capacity that that determination is binding and the person will either need a guardian, or an agent using a valid "power of attorney" or health care proxy to consent to the procedure.[178]

"Expert" Evidence

While, generally speaking, only a judge can take away the right of an adult to act on his or her own behalf and appoint a guardian to make and carry out decisions for him or her, this decision is determined by the evidence presented to the judge. The overwhelming majority of state guardianship statutes require the submission of evidence by a medical expert.[179] This evidence is often submitted in the form of a written report that is rarely subjected to rules of evidence, although in contested hearings even a report that is required by statute may be considered hearsay—and therefore excluded from consideration by the judge—if the expert is not present in court to explain his or her findings.[180]

[I]n many states, it is enough that the professional have the required degree, such as a medical degree, regardless of whether he or she has any specialized knowledge that would aid in making a capacity determination.

Anecdotally, physicians with expertise in cancer or gerontology may be appointed to evaluate the capacity of a young person with cerebral palsy, and individuals have been determined incapacitated after failing a math quiz administered first thing in the morning or being unable to count backward from 100 by multiples of seven.

Some state statutes contain specific requirements regarding the level of expertise and professional training of physicians and others appointed as "experts" who advise the court regarding an individual's capacity. However, in many states, it is enough that the professional have the required degree, such as a medical degree, regardless of whether he or she has any specialized knowledge that would aid in making a capacity determination.[181] Some view this as indicative of a lack of due process given that courts are usually required to make a finding that the testimony offered by an "expert" is relevant and reliable before it will be considered in civil cases that are not in the probate court.[182] Additionally, even in instances in which the court has made such a finding, in many cases so-called *expert testimony* is not subject to the level of scrutiny and cross-examination necessary to assist the fact-finder in weighing the evidence.[183] If behavioral economics undermines the philosophical and legal basis for guardianship, it also raises questions about the decision making processes that physicians, psychiatrists, judges, and others use who contribute to determining an individual's capacity. In practice, the way capacity determinations are made is deeply problematic. Many states rely heavily on physicians and psychiatrists, who provide opinions that are based largely on generalities of a person's

diagnosis rather than on any observable trait of the particular individual. Although statutes that require a physician or psychiatrist to report to the court regarding the capacity of the individual are based on the assumption that these scientists will submit to the court an unbiased and scientifically based opinion, physicians and psychiatrists are often not trained in administering the kinds of tests that may provide the most insight into an individual's ability to make decisions and might not have the requisite skills and experience with the particular disability to render a valid judgment. Anecdotally, physicians with expertise in cancer or gerontology may be appointed to evaluate the capacity of a young person with cerebral palsy, and individuals have been determined incapacitated after failing a math quiz administered first thing in the morning or being unable to count backward from 100 by multiples of seven. Clearly, such "tests" that many people without disabilities would also fail hardly seem sufficient bases for determinations of incapacity leading to the deprivation of one's rights. Often, tests simply confirm what the physician or psychiatrist had already assumed, which is that an individual lacked capacity based on their diagnosis.

Finally, even if they have a clinical basis for determining what a person can or cannot do, the experts that make these determinations may not have sufficient legal context to determine whether the individual is incapacitated as the law defines it. In one study, only 30 percent of doctors were able to correctly apply the definition of legal competence (capacity) in a fact-pattern drawn from an actual legal case. Additionally, although psychiatrists were better able to answer theoretical questions about the standards for legal capacity, they were often wrong when applying those standards to facts. In addition, only a small minority of doctors were able to understand that a person could be diagnosed with dementia or depression and still be legally "competent."[184] Determining legal capacity is a process requiring a medical diagnosis, analysis of functional abilities, and the application of legal principles. Medical doctors simply are not trained in the legal, functional, and medical assessments that could lead to a reliable determination regarding an individual's "capacity."

The job of determining legal capacity becomes even more complex in light of the modern trend toward limited guardianship, which is encouraged in many state statutes, even though studies have shown that plenary guardianships are still vastly more common than limited guardianships.[185] Nonetheless, in order to determine if a limited rather than plenary guardianship might be appropriate, physicians not only have to make a medical diagnosis, assess the person's functional abilities, and determine capacity in light of a legal standard they might not fully understand, they have to repeat this process with respect to

Limited vs. Plenary Guardianships

Limited Guardianship—Instances in which a judge decides that a person can exercise some rights but not others on their own.

Plenary/General Guardianship—Instances in which a judge determines that an individual lacks capacity to exercise *any* of the rights earlier mentioned; the plenary guardian is a guardian of both person and property.

each individual right that may be removed from the person.

Despite the tremendous complexity of the task and the probability that an examining physician or psychiatrist is not well-equipped to make a meaningful recommendation regarding capacity, their opinion regarding capacity is usually given tremendous weight by the court and rarely subject to the crucible of rigorous cross examination or fundamental due process.

Who Are the Experts?

Varies by State

States use a variety of strategies to make capacity determinations. The ABA "Guardianship Law Practice" website contains numerous resources and charts regarding guardianship and alternatives, including a chart detailing the "Representation and Investigation in Guardianship Proceedings." This chart, which is regularly updated to reflect changes to state statutes, shows how capacity is determined in all 50 states and the District of Columbia. The website is well worth looking at for state-specific information as well as a wide variety of resources: https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#statelawsandpolicy. According to the ABA, a few states, including Kentucky and Florida, require the appointment of a panel of three experts to independently evaluate the person's capacity.[186] In Maryland, two physicians or a physician and a psychologist must be appointed.[187] In many states, the court is required to appoint a physician, and in still others, they can appoint a physician or "other qualified person," such as a psychologist, gerontologist, licensed social worker, or licensed counselor to conduct an evaluation and report their findings to the court.[188] In some states, such as Colorado, a "visitor" is appointed to interview the person who is allegedly incapacitated, and in some cases, a physician or other relevant professional is appointed to make a recommendation to the court regarding that person's incapacity.[189] Finally, in some states, a guardian ad litem (GAL) may be appointed to ensure that the person's best interests are adequately represented.

In one case, an attorney who contributed to this report noted having to object when a judge appointed an orthopedic surgeon to evaluate the capacity of a woman with intellectual disabilities.

Guardianship Resource

For state-specific information and a variety of resources on guardianship, visit the American Bar Association's website at https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice.html#statelawsandpolicy.

Shortcoming of Physicians as "Experts"

Although it may seem that requiring a physician to examine the individual provides some assurance that an accurate capacity determination will be made, this may not be the case at all. Even where a physician is required to perform an independent evaluation, physicians

with appropriate expertise and experience may be unavailable or unwilling to perform this type of evaluation. This can lead to physicians being appointed and treated as experts when in fact they have little or no experience with the person's disability. In one case, an attorney who contributed to this report noted having to object when a judge appointed an orthopedic surgeon to evaluate the capacity of a woman with intellectual disabilities. Furthermore, experts in guardianship proceedings may or may not appear in court and even when they do, they are usually permitted to testify as experts merely on the basis of having a medical license and are not required to justify their conclusions by describing methods they used to reach them.[190]

Even in the best-case scenario in which a physician with relevant expertise is appointed, the medical profession's relationship to disability has historically been a paternalistic one.

Even in the best-case scenario in which a physician with relevant expertise is appointed, the medical profession's relationship to disability has historically been a paternalistic one. In medical terms, a *patient* benefits from anything that reverses or ameliorates any disease or disability ". . . that threatens to shorten the life or limit the functional capacity of the patient. Harm is characterized as anything that impedes or compromises the efficacy of those diagnostic or therapeutic measures."[191] This weighs heavily in favor of restricting autonomy in an attempt to ensure safety and may inevitably lead to overly restrictive guardianships. Another anecdotal example we heard from an attorney who practiced guardianship law was a determination by a court-appointed physician that the individual who had sought restoration of her rights continued to need a guardian because, as a person with an intellectual disability and diabetes, she might not be able to follow a diet that would ensure her continued health. This was in spite of her on-the-record testimony that she understood the risks associated with behavior such as eating sweets.

The questions on the MMSE include things like spelling world *backward, stating the year, naming the President, and counting backward by sevens.*

Tools the Experts Use

Tests and Questionnaires

In order to make the extremely difficult job of determining capacity easier, court-appointed physicians and other "experts" appointed to advise the court have numerous tools at their disposal, such as the Mini-Mental State Examination (MMSE), the Short Portable Status Questionnaire, the MacArthur Competency Assessment Test for Clinical Treatment (MacCAT-T), and the Semi-Structured Clinical Interview for Financial Capacity (SCIFC) to name just a few.[192] Of these, the most well-known and most often used is the MMSE, which is a 30-point questionnaire that tests cognitive abilities including orientation to time, place, and verbal recall ability.[193] The MMSE has been used so frequently since its introduction in 1975 that

it has ". . . become the source for cartoons and dark humor."[194] The questions on the MMSE include things like spelling *world* backward, stating the year, naming the President, and counting backward by sevens.[195] Although the test is widely used and has been found to be reliable for assessing the likelihood that a patient has dementia, "[it] has been found in several studies to be less than a sensitive indicator of cognitive abilities relating to decision making."[196] Additionally, the MMSE relies in part on the person's ability to write, making it less reliable when used to assess individuals who are not well educated, who are illiterate, or whose disabilities make it difficult to complete these tasks without proper accommodation.[197] Finally, the test is often administered by individuals who are neither trained in its use nor qualified to interpret the results. For example, some jurisdictions appoint a court "visitor" who is charged with meeting with the AIP and—despite having no medical training or background in clinical assessments—will administer some portion of the MMSE and determine based on the results that the AIP should lose some or all of his or her rights.

Another very common test that is often used with the aging population to screen for dementia is the clock drawing test, which simply requires the individual to draw a clock with the hands pointing to a particular time. An abnormal, inaccurate clock drawing can indicate impairments in cognitive function even when the MMSE score is normal.[198]

Although these tests may be helpful in assessing cognitive decline in the aging, their ability to aid in the determination of whether an individual can exercise a particular right is doubtful. Certainly, no test has put an end to "[the] quest for an objective, uniformly dependable, consistently accurate, and easily administered tool for measuring the mental decision-making capacity of individuals . . .," which has been likened to the quest for the "holy grail."[199]

ABA/APA Framework for Evaluators

Six core elements for clinicians to address in providing capacity evaluations to courts in guardianship proceedings:

1. The specific medical condition causing diminished capacity;
2. Its effect on cognition;
3. Its effect on the person's everyday functioning;
4. The person's values and preferences;
5. Past or imminent risks; and
6. Means to enhance capacity, such as assistive technology or medication.

ABA/APA Framework for Evaluations

Recognizing that accurate capacity determinations are a fundamental requisite to a fair guardianship process and that a single test that can accurately determine capacity is likely to remain elusive, the ABA and the American Psychological Association (APA) collaborated on a series of manuals designed to help lawyers, judges, and psychologists make capacity determinations for older individuals.[200] Although they were somewhat limited in terms of scope, these manuals suggest ways to use direct observation, functional assessments, and

structured interviews to determine capacity. The ABA/APA manual for psychologists sets out core elements for clinicians to address in providing capacity evaluations to courts in guardianship proceedings. These six elements are:

1. The specific medical condition causing diminished capacity;
2. Its effect on cognition;
3. Its effect on the person's everyday functioning;
4. The person's values and preferences;
5. Past or imminent risks; and
6. Means to enhance capacity, such as assistive technology or medication.[201]

For implementation of such an approach, training and collaboration between legal and health communities is warranted, as are consultations between physicians and behaviorists or psychologists. Fair assessments must also include consideration of available alternatives to guardianships in a way that "balances personal autonomy with protection."[202]

While the ABA/APA framework describes the elements of a well-done capacity evaluation, it also emphasizes the importance of finding a professional who has experience in the assessment of capacity of clients with the same type of disability as the individual who is alleged to be incapacitated.[203] As previously discussed, we know that there is extreme variability across the nation as to the nature and quality of assessments and the clinicians appointed to conduct them.[204]

Court Discretion and Due Process

The courts enjoy wide discretion in absence of both consistent criteria and methods for "experts" to use to make capacity determinations and widespread agreement regarding how to balance autonomy and protection.[205] Additionally, guardianship cases are often viewed as objectively benevolent processes that ultimately result in the protection of a vulnerable individual, and this "therapeutic" model of justice ". . . replaces the rigors of adversarialism with the judge's freestyle improvisations."[206] The disconnect between the level of due process that is required in statute and that which is actually practiced in guardianship cases throughout the country is examined in Chapters 4 and 6; however, it suffices to state here that appeals from capacity determinations are rare, and judges are not often overturned unless they are found to have abused their discretion.[207]

[J]udges are not often overturned unless they are found to have abused their discretion.

Limited Guardianship and the Functional Model of Capacity

The move toward a functional, cognitive understanding of capacity that favors an outcome of a limited guardianship as a means of protection may be an improvement over the days when guardianships were always plenary and could be imposed merely because the individual was deemed an idiot, an imbecile, or insane. However, this evolution may have only succeeded in revealing how impossible it is to determine with any accuracy an individual's ability to make decisions in a particular area. Given that, it is worth considering that the whole notion

of "capacity" is "a [legal] fiction determined by prevailing values, knowledge, and even the economic and political spirit of the time."[208] This is the very paradigm shift that led the drafters of the CRPD to recognize the legal capacity of people with disabilities ". . . on an equal basis with others in all aspects of life."[209] This worldwide paradigm shift based in international human rights:

> . . . sees incapacity as socially constructed, insists on the full legal capacity of every person with intellectual disabilities, and does away with substituted decision-making in favor of society's obligation to provide appropriate supports to permit everyone to make his or her own decisions. Like every emerging paradigm, this challenges our perceptions and our understanding of when, how, and even if the state may intervene in a person's life, and it has the potential to be deeply unsettling. And, unsurprisingly, it takes time.[210]

Indeed, a close look at how capacity determinations are made reveals that we may well be tilting at windmills in our noble quest to make refined capacity determinations that only remove those rights that the person is truly incapable of exercising. As Chapter 6 will examine, it also seems unlikely that the due process being provided in guardianship cases is sufficiently robust to yield such refined and accurate outcomes.

Chapter 6: Concerns About When and How Guardians Are Appointed

Guardianship—Greatest Areas of Concern

As we discussed in Chapter 4, existing data on guardianship is limited; however, there is significant evidence that guardianship is a system in continual crisis. Some of the greatest areas of concern include:

- due process protections afforded to individuals subject to guardianship and, in some cases, their families, including making sure alternatives are considered and guardianships are not overbroad;
- inadequacy of capacity assessments, as discussed in Chapter 5;
- the steps the court takes to ensure that an appropriate, qualified, and well-meaning guardian is appointed and that the individual subject to guardianship is not exploited, abused, or neglected by the guardian;
- the ability of courts to adequately track and monitor existing guardianships to ensure that abuse, neglect, and exploitation are not occurring; and
- the ability of the individual to have his or her rights restored at the earliest possible opportunity, including through the use of less restrictive alternatives to guardianship.

While some of these issues have already been discussed in preceding chapters, Chapter 6 will attempt to drill down into these issues and examine them more closely.

Due Process Concerns

Back in 1994, the Center for Social Gerontology conducted a national study that examined the guardianship process in 10 states. The study found that only about one-third of respondents were represented by an attorney during the guardianship hearing(s). While medical evidence was in the court file in most cases, medical testimony was rarely presented at the hearing. The majority of hearings lasted no more than 15 minutes and 25 percent of hearings lasted less than 5 minutes, thus raising questions as to

whether there was opportunity for meaningful due process. Ninety-four percent of guardianship petitions were granted, and only 13 percent of the orders placed limits on the guardian's authority.[211]

Fifteen years later, a Utah ad hoc court committee made similar findings, concluding that:

> [t]he appointment of a guardian or a conservator removes from a person a large part of what it means to be an adult: the ability to make decisions for oneself . . . We terminate this fundamental and basic right with all the procedural rigor of processing a traffic ticket.[212]

[I]n 1994, the Center for Social Gerontology conducted a national study that examined the guardianship process in 10 states . . . [and] found that only about one-third of respondents were represented by an attorney during the guardianship hearing(s).

Near the time of this report, a local news agency had reported on its impressions after witnessing Utah's court guardianship proceedings in action: "[I]t was startling how quickly someone could be stripped of all decision-making rights. Once the paperwork is in order, 'hearings' average seconds, not minutes."[213] It is worth noting that in many jurisdictions magistrate judges hear guardianship cases, which tends to support the notion that these cases are seen as ministerial when in fact they impact fundamental rights.

"[I]t was startling how quickly someone could be stripped of all decision-making rights. Once the paperwork is in order, 'hearings' average seconds, not minutes."

In its report, the court committee went on to list findings that directly impacted the procedural and substantive due process rights of people at risk of or facing guardianship in the state:

- The person subject to the guardianship proceeding was sometimes either not represented or represented by a lawyer recruited by the petitioner's lawyer.
- The lawyer for the person subject to the guardianship proceeding sometimes acted as a *guardian ad litem*, acting in the perceived best interest of the AIP rather than as an advocate for the person's wishes.
- There was no-to-minimal procedure for the person subject to the guardianship petition to elicit and challenge evidence, and the evidence of incapacity itself was cursory.
- Once appointed, guardians were often given the authority of a conservator regardless of whether that authority was warranted by the respondent's circumstances.
- While statutes claimed to prefer limited authority for guardians and conservators, they failed to describe less restrictive alternatives.
- Plenary appointments were common with little evidence to support the need.
- There was no planning to help the person live life as independently as possible.

- There was no regulation of professional guardians.
- There was little education or assistance for family guardians.
- There was little training for judges and clerks.[214]

Based on reports in other jurisdictions[215] and recent scholarship, Utah's court committee is not alone in making these kinds of findings. Guardianship hearings are often brief, relying on incomplete or illegible information, and resulting in plenary appointments.[216] When courts do limit the guardian's authority, individuals are still often treated by those around them as incompetent or incapacitated in every aspect of their lives. Moreover, the person subject to guardianship might not be seen as having an "enforceable right" to participate in decision making in his or her own life even though the statute indicates that that the guardian should consult with the individual; the court proceeding itself can be stigmatizing; and courts frequently do not actively consider alternatives to guardianship prior to appointment.[217]

Guardianship hearings are often brief, relying on incomplete or illegible information, and resulting in plenary appointments.

One can imagine that such violations of due process would have gained the attention of the federal courts. However, for reasons beyond the scope of this report, federal courts generally will not hear challenges to ongoing guardianship cases because of a variety of legal doctrines that are designed to protect the sovereignty of state courts and the ability of judges to make decisions without fear of liability for violating the rights of litigants. Despite this guardianship statutes can be challenged as unconstitutional as written.

Interestingly, the latest example of such a challenge is a challenge to Utah's guardianship statute. In July 2017, the American Civil Liberties Union (ACLU) challenged a Utah law that eliminated a requirement that an attorney be appointed to represents adults with disabilities whose biological or adoptive parents petition courts to become their legal guardians.[218] While advocates for the law say that it helps alleviate the financial burden of seeking guardianship for parents with adult sons or daughters with ID/DD, advocates for people with disabilities are concerned that it means that these individuals will not have a voice in the process or anyone to advocate for them not to lose their civil rights.

In July 2017, the American Civil Liberties Union (ACLU) challenged a Utah law that eliminated a requirement that an attorney be appointed to represents adults with disabilities whose biological or adoptive parents petition courts to become their legal guardians.

Based on the findings of this report, people at risk of or subject to guardianship face many barriers to fair treatment by the legal system. These barriers include problems accessing zealous representation, the overuse of plenary guardianship, disability-specific guardianship processes that raise due process concerns, the inadequacy of capacity

Barriers to Fair Treatment in the Legal System for People at Risk of or Subject to Guardianship

- Problems accessing zealous representation;
- Overuse of plenary guardianship;
- Disability-specific guardianship processes (due process concerns);
- Inadequacy of capacity assessments used to remove rights;
- Lack of court oversight of guardians;
- Burgeoning caseloads; and
- Poor data collection and management

assessments used to remove rights, the lack of court oversight of guardians, caseloads spiraling upward, and poor data collection and management.[219]

Difficulty Accessing Zealous Representation

As in the Utah analysis, some commentators have raised concerns that people facing guardianship or those already subject to it cannot access independent counsel. This is confirmed by a review of information available from the American Bar Association Commission on Law and Aging.[220] The table in Appendix D of this report describes each state's approach to the appointment of counsel. States generally recognize some form of a right to counsel for alleged incapacitated people in preappointment guardianship proceedings. However, depending on the state, that right to counsel may be qualified—for example, by requiring appointment only when the person requests or wants to contest the guardianship; by allowing the court discretion to appoint an attorney; by requiring the person to bear the burden of the legal and expert fees; by limiting a person's choice of attorney; and/or by prescribing the role the attorney plays in the proceeding (i.e., *attorney ad litem* to advocate for what the lawyer believes is in the person's best interest rather than the expressed wishes of the person). This means, in practice, that the appointment of an attorney to advocate for the person's wishes in preappointment proceedings might not always occur. In some cases, lawyers might view themselves in more of a "guardian ad litem" role, meaning they advise the court as to the best outcome for the person. In other words, lawyers might actually provide evidence to the court supporting the appointment of a guardian, even when that is against their client's expressed wishes.

[T]he appointment of an attorney to advocate for the person's wishes in preappointment proceedings might not always occur.

The question of the role of the lawyer in representing the person in preappointment proceedings has been much debated, with most commentators arguing that without a competent and zealous advocate, the person could face unnecessary restrictions on liberty and autonomy without due process.

Overuse of Plenary Guardianship

Empirical studies indicate that courts do not take advantage of the limited guardianship

option and rarely limit a guardian's authority.[221] Most guardianship orders are not time-limited and so last until the subject's death or a court modification or termination of the order, even though an individual's capacity can change over time. For example, psychosocial conditions are often temporary or episodic, and people may experience improvement or fully recover their decision making capabilities within a relatively short time period. These kinds of condition fluctuations are often not appropriately accounted for in either the initial decision to appoint a guardian or in the duration of the guardianship order.[222]

As one scholar postulated, "[a]s long as the law permits plenary guardianship, courts will prefer to use it," even though such guardianships are only appropriate in a sub-set of cases.[223] Courts may make more global assessments of incapacity than are actually justified, based on stereotypes that lead them to undervalue the competencies and/or credibility of people with certain conditions, such as psychosocial conditions or ID/DD. Courts also may not make the proper distinction between what they perceive as the rationality of a person's decision and what that person's actual ability to make a decision is. Additional factors may be a court wanting to err on the side of protection, experiencing difficulties in determining the exact areas of decision making in need of assistance, desiring to avoid confusion about the scope of the guardian's authority, and wishing to promote judicial economy by avoiding future proceedings to expand the scope.[224]

Empirical studies indicate that courts do not take advantage of the limited guardianship option and rarely limit a guardian's authority. Most guardianship orders are not time-limited . . . even though an individual's capacity can change over time.

Unequal Treatment Under the Law for People with ID/DD

There are an estimated 4.7 people with developmental disabilities in the United States, including those with intellectual disabilities, and guardianship disparately impacts this population in a number of ways.[225] In many states, it is easier to obtain guardianship of people with intellectual and developmental disabilities than of others because the process they are subject to is distinct from individuals whose lack of capacity stems from disabilities that arise after one has become an adult, such as dementia, head injury, and psychiatric disabilities. The table in Appendix B lists the states that have distinct guardianship statutes for adults with ID/DD. These statutes are invariably designed to make it easier for parents to get guardianship of children with intellectual and developmental disabilities when they reach the age of majority. Often, they provide for:

> . . . an abbreviated proceeding for individuals with mental retardation when they reached the age of eighteen. The underlying assumption was that [people with intellectual disabilities] were perpetual children, such that the legal powers all parents had over persons under eighteen should simply be extended indefinitely for the parents of [people with intellectual disabilities] . . .[226]

Ryan King

Sometimes, these alternative guardianship processes are viewed and described as "less restrictive alternatives to guardianship." However, although the process used to establish the guardianship may be less expensive and less onerous for parents and others seeking guardianship over an adult with intellectual and developmental disabilities, it is not clear that these types of guardianship are any less restrictive than other forms of guardianship. While some of these alternative guardianship processes, such as Florida's "Guardian Advocacy" statute, F.S. 393.12, are more recent developments, some have been on the books for a long time.

One such example is New York's Article 17-A, which has remained largely unchanged since 1969, other than amendments in 1989 that broadened the types of "developmental disabilities" covered by the statute. While these statutes vary in significant ways, one common factor is that it is less burdensome to "prove" that a person with a developmental disability lacks capacity and/or needs a guardian than it typically is when other disabilities are present. To this point, New York's Article 17-A has been criticized in the following ways: 1) as diagnosis driven rather than based on a functional assessment of capacity; 2) as lacking due process as there is no requirement of a hearing and the person with developmental disabilities is not required to attend if one does occur; 3) as lacking a process for periodic review of the continued need for guardianship; 4) as lacking reporting requirements that make the guardian accountable to the court for the health and welfare of the person subject to guardianship; and 5) that guardianships under Article 17-A are plenary.[227]

In a few states, the statute specifically avoids the question of capacity by providing that a guardian can be appointed for a person with developmental disabilities who needs decision making assistance without an adjudication of incapacity. For example, in Florida a "guardian advocate" can be appointed for a person with developmental disabilities ". . . if the person lacks the decision-making ability to do some, but not all, of the decision-making tasks necessary to care for his or her person or property or if the person has voluntarily petitioned for the appointment of a guardian advocate."[228] A guardian advocate appointed under this statute has generally the same rights and responsibilities under Florida's more general guardianship statute. The main difference is that, since the individual is not technically considered "incapacitated," the rights that can be removed from the person but not transferred to the guardian—such as the right to vote or seek employment—are not taken away from the individual. However, if the right to contract has been transferred to the guardian advocate, the individual who is the subject of a guardian advocacy is not entitled to marry without court approval as that is legally a contractual arrangement. Although Florida's guardian advocacy is considered by some to be a less restrictive alternative to guardianship, it is essentially a limited guardianship with fewer due process protections afforded to the person with a developmental disability under this statute.

Many families are grateful for less onerous paths to establish guardianship in instances in which the family and the individual's interests are aligned and where the lack of capacity or need for decision making assistance is readily apparent. However, the short shrift given to due process, the cursory nature of the capacity determination, and the lack of focus on viable alternatives to guardianship make these statutes problematic against the backdrop of overall policy aims of promoting self-determination and less restrictive alternatives to guardianship whenever possible. Additionally, families who seek guardianship under these processes may feel pressured into a less-than informed decision without fully understanding the implications of guardianship or the possible alternatives.

The suggestion of guardianship usually first arises at an individualized education program (IEP) meeting when a child with a disability nears the age of majority.

Rights are not easily restored once they've been removed by a guardianship. In fact, there have been examples of families who later regretted seeking guardianship for their grown children with ID/DD, only to encounter a difficult time convincing the courts to allow them to use alternatives that would meet the individual's needs. In September 2015, the *Washington Post* chronicled the story of Ryan King, an adult with ID/DD who was subject to guardianship. When Ryan turned 18, his parents were told they had to become his guardians in order for him to receive adult services. In 2007, Ryan's parents asked the Court to remove them as his guardians, saying that he did not need or want to be under guardianship. By that time, King had worked at a grocery story and used supported decision-making with his parents for years. However, the court denied their request. It was not until nearly 10 years later that the court

eventually terminated Ryan's guardianship, after he found new attorneys to represent him and present expert evidence supporting his functional capacity and effective use of supported decision making."[229]

School-to-Guardianship Pipeline for Youth with ID/DD

The Pipeline Problem

The suggestion of guardianship usually first arises at IEP meeting when a child with a disability nears the age of majority. Children who have IEPs under the IDEA are entitled to receive services until they graduate from high school or they reach age 22. Children with disabilities may have a difficult time graduating at the expected pace for a variety of reasons. However, these delays should not undermine the presumption of capacity for those that have reached the age of majority, which is 18 for most purposes with the exception of the drinking age. Be that as it may, parents are often informed by teachers or administrators that the rights that parents have under IDEA, for example to participate in IEP meetings and to due process if there is a dispute over the content of the IEP, will transfer to the child when they turn 18. In theory, this takes place in the context of a fulsome transition plan designed to help the child take on the adult responsibilities of employment or higher education and vocational training. However, too often this notice is issued as a warning to parents alongside a suggestion that they need to obtain guardianship over their children with ID/DD in order to continue to participate in their education and to protect youth who are often seen as incompetent and potentially vulnerable to abuse or exploitation due to their disabilities. While such concerns should not be taken lightly, it is worth noting that *all* parents have fears about whether their teenager will be ready for the responsibilities of adulthood when they turn 18, but it is only the parents of teenagers with disabilities who are regularly advised that they have the option of preventing the child from becoming legally an adult in the eyes of the world.

[A]ll parents have fears about whether their teenager will be ready for the responsibilities of adulthood when they turn 18, but it is only the parents of teenagers with disabilities who are regularly advised that they have the option of preventing the child from becoming legally an adult in the eyes of the world.

In 2008, researchers found that in one school for children with developmental disabilities, faculty encouraged all parents to obtain guardianship when their children turned 18. Furthermore, faculty had few reservations or second thoughts about concluding that their students needed guardianship, as they were largely motivated by a perceived need to protect the young adults and believed the way to do this was by pursuing guardianship. Frighteningly, researchers found that the faculty lacked knowledge regarding the guardianship process and about alternatives to guardianship.[230]

Evidence suggests that parents of young adults with disabilities are often seeking guardianship when their children turn 18 and are still in school. One study examined 221

guardianship files across nine jurisdictions in Michigan that were filed under Chapter 6 of the Michigan Mental Health Code, which governs guardianships for people with developmental disabilities. They found that more than 50 percent of the individuals in the sample were 18 when the guardianship petition was filed and more than 90 percent were still in public schools when the petition was filed. Interestingly, for approximately half the individuals in the study, the sole income was SSI.[231] While it is not altogether surprising that parents are seeking guardianship over young adults with intellectual disabilities at a relatively young age, it does suggest that guardianship in these cases is being filed proactively (prior to these young adults attempting greater independence first) and perhaps without a full consideration of the alternatives, since the young adult had a guardian as a child (as do all children) and continues to have one as an adult. In fact, numerous alternatives exist that could alleviate the main concerns that parents have at this important juncture in their children's lives. These alternatives are explored more fully in Chapter 9, but it's important to note that in many cases these alternatives already exist without any need for statutory changes.

For instance, a young adult who has not completed high school by the time they're 18 can voluntarily elect to continue to include their parent in their IEP meetings, or in some states there is a process for the school to recognize the parent as the representative of an adult child with a disability for IDEA purposes upon a determination that the individual is unable to participate meaningfully in the process. With respect to medical decisions, there is usually a provision that provides for the next of kin to consent to medical treatment on behalf of a person 18 years of age or older, who "lacks capacity to understand appropriate disclosures regarding proposed professional medical treatment . . ."[232] In such cases, capacity is determined in reference to medical personnel determining that the person cannot provide informed consent to medical procedures rather than a judicial proceeding. Finally, a person who receives SSI due to an intellectual disability will often have a representative payee appointed to manage their benefits, alleviating the need for a conservator or guardian of property if the monthly benefit is the individual's only source of income. With these three alternatives in place, the need for guardianship is greatly reduced.

If guardianship is a family's first choice rather than the last resort after other alternatives have been tried (or at least seriously considered and rejected), the negative impact may not be limited to the young person with a disability who finds his or her rights curtailed more than necessary. Obtaining guardianship can be an expensive and arduous process for families, too, and the ongoing reporting requirements may prove too much for some. These may be acceptable trade-offs where guardianship fulfills the perceived need to protect the individual; however, there are reasons to ask whether guardianship is actually helpful in many cases, even where the individual's lack of capacity seems readily apparent.

There is a great deal of evidence that special education teachers regularly encourage or even pressure parents into seeking guardianship of their transition-age children with disabilities. For example, a 2015 study supported by the TASH

Human Rights Committee and the Alliance to Prevent Restraint, Aversive Interventions and Seclusion (APRAIS) tends to support this conclusion. The study analyzed 1,225 responses to an online survey regarding their experiences with guardianship and alternatives. Eighty-seven percent of respondents were parents of people with disabilities. Thirty-seven percent of respondents indicated that they or the person about whom they were answering questions had a guardian, and 63 percent did not, although of the latter group, 37 percent indicated that guardianship had been recommended. When asked, "Who first suggested guardianship?" the most common response was "school personnel." Strikingly, the survey results indicated that regardless of who first made the recommendation, plenary guardianship and "power of attorney" were the most often recommended option for decision making assistance across every IDEA disability category except deafness, recommended with equal frequency.[233]

There is a great deal of evidence that special education teachers regularly encourage or even pressure parents into seeking guardianship of their transition-age children with disabilities.

Alternatives to the Pipeline

While clearly some parents are receiving encouragement to pursue guardianships over their children with disabilities, there are also signs pointing to some families increasingly learning of alternatives to guardianship and getting better advice to help them weigh their options. These changes are likely due in part to changing attitudes toward disability generally, a growing awareness and recognition of alternatives such as supported decision making and changing expectations regarding employment for young adults with disabilities such as seen in the 2014 Workforce Innovation and Opportunity Act (WIOA).[234]

Workforce Innovation and Opportunity Act (WIOA)

Section 511 of WIOA limits the ability of employers who hold 14(c) certificates from the U.S. Department of Labor (which allow them to pay people with disabilities under minimum wage) to pay subminimum wages to any person with a disability age 24 or under, unless they are already employed by such an employer, in which case they are "grandfathered in." Under the new law, holders of these certificates cannot pay subminimum wages to any youth without first documenting that the youth has received transition services under IDEA; has applied for Vocational Rehabilitation (VR) services and either been found ineligible or had their case closed after working toward an individual plan for employment (IPE) goal for a reasonable period of time; and has received career counseling. These limitations are intended to make it less likely that youth will be inappropriately routed into segregated, subminimum wage employment without exploring all the alternatives for meaningful work and post-secondary education and training. WIOA has the potential to be transformative in terms of societal expectations of young people with intellectual and developmental disabilities, and it may be that these raised expectations will

make guardianship less of a foregone conclusion as well.

State Efforts to Promote Alternatives to Guardianship

Some state education agencies are making a genuine effort to make sure that parents' desire to continue to be involved in their children's education is not a reason for guardianship. For example, the D.C. Office of the State Superintendent of Education website specifically encourages the use of supported decision making for students who may need assistance to ". . . make his or her own decisions, by using adult friends, family members, professionals, and other people he or she trusts to help understand the issues and choices, ask questions, receive explanations in language he or she understands, and communicate his or her own decisions to others." Additionally, the site provides a form ". . . to provide assistance to local education agencies (LEAs) and adult students to document supported decision-making decisions. . . ."[235]

Some state education agencies are making a genuine effort to make sure that parents' desire to continue to be involved in their children's education is not a reason for guardianship.

Another example is the "I'm Determined" project funded by the Virginia Department of Education, which focuses on providing direct instruction, models, and opportunities for students to practice skills associated with self-determined behavior, including effectively participating in their IEP.[236]

Many family-based groups not affiliated with a state education agency are also trying to improve on the information that is available to families at this critical juncture. "Family Voices" of Wisconsin has a fact sheet on "Supported Decision Making for Transition Age Youth" that provides valuable information about alternatives to guardianship and how to use supported decision making effectively in this context.[237]

[S]tate DD Councils have also launched initiatives designed to encourage the full consideration of alternatives to guardianship and make sure people with ID/DD and their families have complete information . . .

Finally, state DD Councils have also launched initiatives designed to encourage the full consideration of alternatives to guardianship and make sure people with ID/DD and their families have complete information when deciding whether they need to resort to guardianship. One such initiative is "Lighting the Way to Guardianship and Alternatives," funded by the Florida Developmental Disabilities Council, which provided trainings across Florida for individuals and families as well as legal professionals interested in knowing more about guardianship and alternatives.[238]

Financial Costs of Guardianship

Throughout this report, we have made the case that the adjudication of incapacity and

the imposition of guardianship is a serious deprivation of constitutional rights. To the extent that the traditional parens patriae authority can be used to subject an individual to guardianship, the decision to do so must be reached through due process. However, to put it bluntly—due process is not cheap. Even where every person in the guardianship system is working with the interests of the person with a disability in mind, the person can emerge from the process much poorer than they entered it. Where an individual subject to guardianship is indigent, the costs often fall on the state, and given the relative stinginess of state budgets in the last 10 years, there are real gaps in funding that make it impossible for the system to work for the people it is supposed to be supporting and protecting.

As often noted, simply describing guardianship can be difficult because of tremendous differences in statutes from state-to-state, as well as differences in practice from court-to-court; differences in the dynamics with family guardians, professional guardians, and public guardians; differences that stem from the reason for guardianship, whether it's ID/DD, dementia, mental health, head-injury, or another cause; and whether the guardianship is "contested" or not. Similarly, each of these factors can alter the financial aspects of guardianship. Additionally, the local economy can impact the cost of guardianship a great deal; simply put, professional guardians, lawyers, and other actors may charge vastly more for their services in Miami than they would in Pella, Iowa. However, there are some fundamental issues related to the costs associated with guardianship that we can explore. Please note that this may be related to the conversations around financial exploitation, but here we are really focusing on costs that occur even in the absence of any intent on the part of the guardian or any other actor to unjustly enrich themselves.

Cost of Justice

Even the most straightforward, uncontested guardianship case can be quite expensive. Estimates of the average cost of obtaining guardianship range from as low as $1,500 to as high as $5,000 and even higher. Contested guardianships where the individual does not agree that they need a guardian or where there is disagreement over who should be appointed as guardian can be even more costly. These estimates may include initial filing fees, paying an attorney to represent both the individual subject to guardianship and the putative guardian, and fees associated with the determination of incapacity, such as paying a psychiatrist to examine the alleged incapacitated individual and report their findings to the court. Once the guardianship is established, the guardian is generally entitled to receive a reasonable fee for their services out of the estate of the person subject to guardianship. In addition, the guardian will often—and in some states is required to—retain an attorney to represent the guardianship, that attorney is also paid out of the estate of the person subject to guardianship. When guardians are required to file documents that facilitate the court's ability to monitor the guardianship, such as annual accountings and

Estimates of the average cost of obtaining guardianship range from as low as $1,500 to as high as $5,000 and even higher.

reports, they are usually entitled to be paid for the time it takes to prepare the documents, and the attorney for the guardianship can collect a "reasonable fee" for the time it takes to review the documents and file them with the court.

A majority of states' statutes establish "reasonable fees" as the standard for how much a guardian can be paid for the work that they do. In 2013, the Florida State Guardianship Association (FSGA) conducted a survey about the fees charged by the 400 professional guardians who were members of the organization at that time. Of those, 130 responded. The range of fees was quite broad, with the lowest fee coming in at $15 per hour and the highest fee being $125 per hour; it's worth noting that the range of experience of the professionals was also quite broad, with some of the guardians reporting that they were just starting out and others reporting that they had more than 20 years of experience as professional guardians. The most common rates reported were between $45 and $85 per hour. Additionally, the survey found that most guardians set their rates in accordance with local court rules or customs. Twenty-five percent of respondents reported that their fee varied based on the activity and almost 13 percent reported that the courts set limits on the amount of time that particular activities should take and limit fees assessed accordingly.[239]

In 2013, the Florida State Guardianship Association (FSGA) conducted a survey about the fees charged by . . . 400 professional guardians. . . . The range of fees was quite broad, with the lowest fee coming in at $15 per hour and the highest fee being $125 per hour . . .

In Florida as well as other states, significant questions can arise regarding the nature of the work performed. For example, the reasonable fee that an attorney can charge for their legal services may be different than what they can charge when they are acting as the guardian for an individual, as lawyers often do. Another facet of this issue is how much guardians can charge for performing tasks that do not require the experience and training that a professional guardian might be expected to have. For example, if a guardian visits a person subject to guardianship and, while they're there, spends two hours helping the individual clean up their living space they are probably not entitled to charge $125—which might be considered a reasonable fee for a guardianship service, but probably not for housekeeping services. The National Guardianship Association (NGA) standards address this issue and provide guidance on time records. At a minimum, accountings filed by a guardian should include a detailed description of the task performed to allow the court to determine whether the activity justifies the professional guardian's hourly rate or a lesser rate that is commensurate with the activity. However, many courts lack the personnel, expertise, and resources to closely review these reports or confirm their accuracy.

Finally, while most of this discussion concerns the ability of professional guardians to charge for their services, the UGGPA and the updated version, the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act, provides that guardians can be paid out of the guardianship estate for

their services irrespective of whether they are professionals or family members. However, family members are not necessarily able to claim the kinds of hourly rates professional guardians are able to based on training and experience. Additionally, family members are not generally entitled to compensation for services that are the kind family members usually perform for each other but only for services that fall within the scope of the guardianship (e.g., paying bills).

Public Funding of Guardianship

In addition to the critique of guardianship that it potentially drains the person's resources under the guise of preserving them, there are issues related to public funding of guardianship. In most states, public guardianship is a mechanism to provide decision making services for an individual who has been determined to need a guardian, but for whom no qualified individual has stepped forward to serve as guardian. Additionally, in some states, public guardianship is specifically for individuals who are indigent or of limited means while in few others public guardianship is limited to people with specific types of disabilities. A national study of public guardianship in 2007 found that public guardianship essentially falls into four categories: 1) the public guardian is an official of the court and is appointed by the chief judge of the court; 2) a statewide public guardianship office that is part of the executive branch of state government; 3) the public guardian is an arm of a preexisting social service agency; and 4) the public guardian is a county agency. Within these three models of public guardianship, funding streams may vary dramatically, but across the board, public guardianship systems are under-funded. There are significant unmet needs for public guardianship across the country as well as for other decision making services for individuals who do not have close family or friends willing or able to provide assistance. The 2007 study found that funding for public guardianship comes from a patchwork of sources, but that none are sufficient. This can lead to incredibly heavy caseloads for public guardians, raising concerns about the quality of the services provided. Additionally, the report points out that individuals who are in institutions but may be able to transition to the community may need a public guardian to advocate for such a move and to make the necessary arrangements, but not be able to access one because the public guardianship system is chronically under-funded.[240]

[I]ndividuals who are in institutions but may be able to transition to the community may need a public guardian to advocate for such a move . . . but not be able to access one because the public guardianship system is chronically under-funded.

Additionally, some of the ways that public guardianship systems operate are inherently problematic. For example, the study found that in 2007, 32 states used a social services agency model for public guardianship. In this scenario, the authors claim, if the public guardian program is ". . . housed in an entity also providing social services, then the public guardian cannot advocate for or objectively assess services, or bring law suits against the agency on behalf of incapacitated persons."[241] There is clearly a need

for more robust and independent sources of funding for public guardianship.

More public dollars—including federal dollars—must be invested in alternatives to guardianship, which are widely recognized as being not only less restrictive, but also less expensive than guardianship. ACL has funded a number of pilot programs exploring the effectiveness of supported decision making. These projects are discussed in Chapter 8.

Professional Guardianship in the Absence of Sufficient Public Funding

One last interesting finding from the FSGA survey discussed was that "[m]ultiple respondents reported the hourly rate of the guardian being affected by the percentage of pro bono work carried by the guardian."[242] In other words, the estate of one individual subject to guardianship was charged more to compensate the guardian for work performed for an indigent individual. FSGA is careful to note that this practice is inequitable and unfair to the person who is paying more to make up for the unmet need for public guardianship in the community, but anecdotally this practice persists in Florida and other states. Although a discussion of financial exploitation by guardians is offered elsewhere in the report, it's worth noting that practices can lead to the perception, whether accurate or not, that professional guardians are "fleecing" their clients. Families of individuals subject to guardianship, who may have their own stake in preserving assets they anticipate inheriting one day, often perceive guardianship as ". . . a closed system in which attorneys, fiduciaries and other professionals have associations with one another and loyalty to each other that may potentially override their professional responsibilities."[243] This perception may or may not be correct, but given previously identified significant shortcomings regarding the court's ability to monitor guardianships or to subject accountings to any kind of close examination, it is easy to understand why some would jump to the conclusion that judges, lawyers, and professional guardians are engaged in a conspiracy to defraud their loved one. Ironically, their loved one may be being overcharged in part because the professional guardian has a large pro-bono caseload. This may be compounded by the fact that professional guardians and the attorneys who represent them may have to respond to actions taken by the family members of an individual subject to guardianship, and they are usually entitled to their hourly rate to do so. With hourly rates for probate attorneys reaching as high as $350 an hour and even higher in some regions of the country, this can very quickly make the costs associated with guardianship at least appear excessive. This can spiral into a scenario where everyone is pointing the finger of blame at each other while the assets that are supposed to be preserved and used to meet the individual's needs are rapidly depleted, even though no one involved intended any harm to the "protected" individual.

Several states have created oversight mechanisms outside of the judicial apparatus that are intended to regulate public and professional guardians, while those efforts are mostly aimed at addressing issues of fraud, they may have the impact of preventing the type of spiraling fees scenario previously described. The Office of Public and Professional Guardians (OPPG) in Florida, for example, created a mechanism for reporting complaints regarding a professional

guardian and the ability to sanction guardians, including suspension or revocation of their certification as professional guardians, without filing the complaint with the court. This may help detect and address situations where the guardian is actually committing abuse or failing to discharge their duties, but it also may prevent unnecessary and expensive judicial procedures in some cases. Additionally, OPPG can assess whether multiple complaints have been registered against a particular guardian and respond accordingly, whereas a court might not know that several people have issues with the same guardian's actions.[244]

Chapter 7: Concerns Once Guardianships Are in Place

Overview of Concerns

Many of the individuals interviewed for this report told NCD that, in their experience, guardianship is an extremely dysfunctional system. Not only are there serious deficiencies in terms of the due process that is afforded to individuals facing losing their rights in a guardianship proceeding, there are significant problems once a guardianship has been established. National advocacy organizations and the media have highlighted the abuse of guardianships and conservatorships as a means to exploit people with disabilities and older Americans. Unfortunately, the ability of courts, advocates, and others to address this issue has been impeded by a number of factors, including the absence of accurate national information regarding the numbers of people affected by guardianships, the conditions under which a guardianship is imposed, the services and alternatives being offered, the frequency and nature of misfeasance by guardians, and the possible warning signs of abuse. However, several states are taking steps to increase their efforts to effectively monitor guardianships to ensure that individuals who find themselves subject to guardianship are protected from abuse, neglect, and exploitation by their guardians. Additionally, as previously noted, the President signed legislation in 2017 that attempts to assist states in their efforts to ensure that older people, including those subject to guardianship, are protected from abuse.[245]

Guardianship has been referred to as a double-edged sword—*an instrument designed to protect vulnerable people in society from abuse or neglect, while simultaneously removing fundamental rights that may increase opportunities for such abuse.*

Guardianship: A Double-Edged Sword?

Guardianship has been referred to as a *double-edged sword*—an instrument designed to protect vulnerable people in society from abuse or neglect, while simultaneously removing fundamental rights, which may increase opportunities for such abuse.[246] As Professor Michael Perlin stated, "At best, the guardianship will provide the personal care and property management that the [person with a disability] alone cannot handle. At worst, guardianship will deprive the individual of decision-making authority that he or she has the capacity to

handle, and create the opportunity for personal or financial abuse."[247]

Guardianship affects a person's legal right to make some or all of the decisions in their lives, including those about finances, health care, voting, marriage, socializing, and working, among others. Guardianship can easily go beyond protecting rights and seriously interfere with self-determination, especially if guardians exercise control in areas where persons could make their own decisions either with or without support.[248] Another legal scholar expressed concerns that "the total power which the law gives to guardians creates the possibilities for isolation and vulnerability that leads to, or at least permits, abuse."[249]

While there are certainly many cases where families have made guardianship work for them, as well as many professional guardians who have taken the National Guardianship Association "standards of practice" and ethical guidelines to heart to promote the well-being and self-determination of people subject to guardianship, there are also many examples of overly restrictive guardianships and of financial, physical, and emotional abuse perpetrated by unscrupulous guardians. This chapter will explore some of the consequences of guardianship and propose recommendations for change.

The Impact on Life Outcomes

The justification for guardianship is that it is a means of protecting vulnerable individuals. However, when A. Frank Johns, an elder law scholar who often writes about guardianship, surveyed 22 projects, studies and conferences from 1961 to 1996, he was not able to identify any findings that clearly showed that guardianship leads to positive life outcomes for people who are subject to it. Even if they can show that guardianship preserves property, those prior investigations ". . . have also uncovered evils in guardianship: removing all rights; denying access, connections, and voice to those lost in guardianship's gulag; and still continuing a process rooted in systemic perversities."[250]

Guardianship's Impact on Life Outcomes

In a survey of 22 projects, studies, and conferences from 1961 to 1996, elder law scholar A. Frank Johns was unable to identify any findings that clearly showed that guardianship leads to positive life outcomes for people who are subject to it.

Johns wrote that the more recent studies of guardianship monitoring and public guardians "acknowledge that guardianship still limits the autonomy, individuality, self-esteem, and self-determination" of those subject to guardianship, and he expressed continued concerns that the legal system surrounding guardianship focused more on the interest in protecting a person's property than the person him/herself.[251]

Guardianship orders impact the very decisions that define people as human beings, and thus have significant impact on the daily lives of people subject to them. Studies have found that, when a person loses the right to make his or her own decisions, there will likely be a negative impact on the person's functional abilities, physical and mental health, and general well-being. One scholar talks about the "constructive isolation of guardianship" and its impact on

people.[252] People subject to guardianship can "feel helpless, hopeless, and self-critical" and experience "low self-esteem, passivity, and feelings of inadequacy and incompetency," as well as significantly decreased "physical and mental health, longevity, ability to function, and reports of subjective well-being."[253] Some scholars also argue that, because guardianship is sought based on a finding that a person lacks capacity, it can be demeaning and socially stigmatizing.[254]

Financial Abuse by Guardians

Although guardians are often appointed to protect an individual's assets from waste or to prevent a "bad actor" from obtaining access through undue influence, fraud, or misrepresentation, ironically this often places guardians in the best possible position to financially exploit vulnerable individuals themselves. Two recent GAO reports attempt to ascertain the scope of this problem. Both reports focused on financial abuse of only seniors but, as noted previously, individuals are only subject to guardianship if they are "incapacitated," which clearly means that, while the reports may not examine younger people with disabilities subject to guardianship, the senior individuals described in these reports are people with disabilities. In both reports, GAO noted that a lack of accurate data on guardianships made it impossible to determine whether guardianship abuse is widespread.[255] However, the 2010 report detailed the cases of 20 guardians who improperly obtained $5.4 million in assets from 158 incapacitated victims.[256] In addition to the theft or improper obtainment of assets, in some instances, guardians also physically neglected and abused their victims. The guardians in these 20 cases came from diverse professional backgrounds and were overseen by local courts in 15 states and the District of Columbia.

Studies have found that, when a person loses the right to make his or her own decisions, there will likely be a negative impact on the person's functional abilities, physical and mental health, and general well-being.

GAO found several common themes across the 20 cases. In 6 of 20 cases, the courts failed to adequately screen potential guardians, appointing individuals with criminal convictions or significant financial problems to manage high-dollar estates. In 12 of 20 cases, the courts failed to oversee guardians once they were appointed, allowing the abuse of vulnerable seniors and their assets to continue. Lastly, in 11 of 20 cases, courts and federal agencies did not communicate effectively or at all with each other about abusive guardians, allowing the guardian to continue the abuse of the victim and/or others.[257]

[T]he 2010 [GAO] report detailed the cases of 20 guardians who improperly obtained $5.4 million in assets from 158 incapacitated victims.

In a more recent report published near the end of 2016, GAO found that while these problems persisted, states and federal agencies had begun to take steps to at least collect better data that can not only guide policymakers but also can

catch malfeasance earlier. One such positive step that GAO identified in their report is the development of the National Adult Maltreatment Reporting System (NAMRS), a national reporting system based on standardized data submitted by state adult protective services (APS) agency information systems.[258] In a hearing before the Senate Special Committee on Aging addressing the 2016 GAO reports findings, Cate Boyko, manager of the Conservator Account Auditing Program for the Minnesota Judicial Branch testified about the state's "Conservator Account Monitoring Preparation and Electronic Reporting" system, better known as "CAMPER." This electronic records system allows guardianship records to be monitored continuously for red flags that might indicate that exploitation is occurring. Additionally, it provides accurate and easily accessible data that can be audited on a regular basis to ensure that guardians of the property are managing money prudently and not engaging in exploitation. In order to encourage adaptation of this system to meet the needs of other states, CAMPER's source code has been made available to other states who may want to replicate the system.[259]

Overbroad Guardianship

As discussed in Chapter 3, limited guardianships were an important innovation in the second wave of guardianship reform, but its use remains inconsistent across the United States. In some cases, judges and professionals may draft overly broad guardianship orders to prevent parties having to return to court to expand the guardians authority as a disease such as Alzheimer's progresses. Indeed, having to return to court in a guardianship case can have the effect of depleting the resources of the individual subject to guardianship, because unless indigent, he or she is ultimately on the hook for paying all the costs associated with guardianship. In several states there is a requirement that the individual be represented by counsel whenever they are faced with losing rights under guardianship. This means that, at a minimum, their estate will have to pay for two lawyers—one representing the person who is already under a limited guardianship but who allegedly lacks capacity in an additional area, as well as the guardian's lawyer, who would normally be urging the court to expand the guardian's authority—and for the fees assessed for the examination that would be required to determine the individual lacked capacity in an additional area. It is easy to see

how this can quickly become a costly endeavor. However, a guardianship that removes more rights from the individual than necessary is legally and morally impossible to justify, even if there is a financial argument for it.

As discussed elsewhere in this report, restoration cases can be similarly costly, and it may be that establishing guardianships that are overly broad may lead to an increase in petitions for restoration. As discussed further in Chapter 8, there are numerous alternatives that can be used instead of guardianship; these tools should also be used when possible to limit the scope of guardianship. However, given the difficulty identifying discreet areas of incapacity described in Chapter 5 and the financial and judicial economy arguments previously outlined, it seems unlikely that courts are going to truly embrace limited guardianships in the way we might have hoped.

Implications for Voting

> *I think that one of the ways that you can really silence someone and make them feel not a part of society is by taking away something that's as fundamental as the right to vote.*
>
> —NCD Interview Participant

As NCD noted in its 2013 report, *Experience of Voters with Disabilities in the 2012 Election Cycle*, federal laws such as the Help America Vote Act (HAVA) have tended to focus on physical access to the polls by people with disabilities, "yet competency requirements imposed by state laws or by election officials or service providers also present challenges for voters with disabilities." Thirty-nine states have laws that restrict the right to vote based on competency: 25 states require a court to specifically determine that the individual lacks the capacity to vote in order for incapacity to justify disenfranchisement; 10 states provide that a person "under guardianship" is barred from voting outright; 4 states bar those who have been deemed "non-compos mentis" from voting (defined differently in each state); and 7 states prohibit "idiots," "insane persons," or those of "unsound mind" from voting.[260] Along with other aspects of guardianship law described in Chapter 2:

> the rationale for disenfranchisement changed from one of dependency as a marker of who was or wasn't a full political citizen, to perceived lack of mental competency in the mechanics of voting. All the while, the legal system maintained that lunatics and idiots did not possess the requisite minds for voting.[261]

This issue rose to national prominence in the 2016 election. As widely reported at the time, a former National Public Radio producer named David Rector was placed under conservatorship following a brain injury. He went to court to ask for restoration of his right to vote under California law,[262] which changed in 2016. Under the new law, the court could only remove the right to vote after making a specific finding that the individual was unable to express a desire to vote. Mr. Rector was successful in getting his right to vote restored, and his story raised awareness of this important voting rights issue.[263] Sadly, in most states, individuals who are subject to guardianship may not realize that they could lose their right to vote even if the subject of voting is never raised at the guardianship hearing. These determinations that an individual is incapable of voting can be

challenged as discriminatory if they remove the right to vote from individuals due to disability or supposed "mental incompetence" despite there being no specific finding that the person lacks the ability to make decisions specific to voting. On the other hand, where courts do seek to explore whether an individual subject to guardianship should be allowed to vote, "[p]robate courts . . . sometimes ask individuals who are the subject of guardianship proceedings to demonstrate an understanding of elections and politics that goes far beyond what is expected of the general public before they are permitted to vote."[264] As previously noted, California is one of four states to have adopted the standard urged by the American Bar Association's House of Delegates, which is that the right to vote should only be removed based on incapacity if the individual cannot express "a specific desire to participate in the voting process."[265] Although Maryland, Nevada, and New Mexico are the only other states that use this standard, the standard is nonetheless consistent with the Voting Rights Act, which prohibits states from applying restrictive and unequal tests to determine who is qualified to vote.[266]

Sadly in most states, individuals who are subject to guardianship may not realize that they could lose their right to vote even if the subject of voting is never raised at the guardianship hearing.

Some express concerns that allowing people with significant cognitive disabilities to vote could lead to widespread voter fraud. There is some evidence that voters in long-term care facilities who utilize absentee voting are vulnerable to this kind of fraud.[267] However, it is not clear whether individuals who are subject to guardianship would, as a group, be more likely to have their franchise abused than other people with disabilities and older individuals.

Sexuality and Guardianship

Sexuality is an incredibly broad and incredibly fraught topic for people with disabilities that raises issues not only about consent and mental capacity, but also "the forced sterilization of [people with disabilities], the rights of [people with disabilities] in institutions to have sex and be free from sexual abuse, and the rights of lesbian, gay, bisexual, and transgender (LGBT) [people with disabilities]."[268] Against this complex backdrop, NCD recognizes that "the desire to enter into intimate personal relationships, including sexual relationships, is one of the most personal rights there is" and that ". . . desire is no less important for the many adults with disabilities who are under some form of guardianship."[269] Although disability and sexuality has long been a taboo subject, and there are still pervasive and destructive myths surrounding disability and sexuality, disability organizations such as The Arc of the United States and the American Association on Intellectual and Developmental Disabilities have long recognized that people with intellectual disabilities must have their sexual rights "affirmed, defended, and respected."[270] Similarly, in the context of guardianship, the National Guardianship Association Standards of Practice provide:

> [t]he guardian shall acknowledge the person's right to interpersonal relationships

and sexual expression. The guardian shall take steps to ensure that a person's sexual expression is consensual, that the person is not victimized, and that an environment conducive to this expression in privacy is provided.[271]

Particularly for people with intellectual disabilities, who many in society frequently describe as having a mentality that correlates with a child's age, society is uncomfortable with the idea of these individuals having sexual feelings, and in some cases justifiably concerned about an individual's ability to make an informed decision about sexual relationships. Concerns about the very real possibility of sexual abuse are too often justified. According to the Bureau of Justice Statistics, between 2011 and 2015, people with all types of disabilities are more than three times as likely to be victims of rape or sexual assault as their peers without disabilities, and people with cognitive disabilities were the most likely to be victims of all types of violent crimes among the disability types measured.[272] National Public Radio reports that, according to unpublished Justice Department data, the risk of sexual abuse faced by people with intellectual and developmental disabilities may be seven times higher than for the general population.[273] NCD has long recognized that "rights protection programs must be established to reflect the fact that women and girls with disabilities are subject to double discrimination in society and require protections against physical and sexual abuse in the family and in the very social programs created by society to serve them . . ."[274] It's worth noting that guardianships can also sometimes arise out of a family's desire to protect an adult child or older loved one who might be vulnerable to sexual abuse and might not be able to offer informed consent to enter into a sexual relationship.

As discussed earlier in this report, all adults are presumed capable of making decisions for themselves. This presumption is true of sexual relationships, as well as expressed by states' age of consent for sexual activity, which is most often between 16 and 18 years old. Additionally, states also define the circumstances of sexual incapacity in which circumstances negate consent, such as intoxication, age, being asleep, being in the custody of the state, or mental disorders.

[G]uardians are uniquely positioned to police with whom the individual subject to guardianship can associate, creating a situation where the individual is only allowed intimate contact with partners of whom the guardian approves.

While no one wants to see predatory or exploitive behavior against individuals who may not be able to consent, or who may have limited ability to express that they are even being victimized, these laws do create confusion regarding the circumstances under which a person who is subject to guardianship, or whose ability to offer informed consent is questionable, could ever have consensual sex. Additionally, guardians are uniquely positioned to police with whom the individual subject to guardianship can associate, creating a situation where the individual is only allowed intimate contact with partners of whom the guardian approves.

In some cases, the guardian might have the person's best interests at heart, but this scenario can also become deeply problematic.

As an example of the problems that can arise, in the case of *In re Guardianship of Atkins*, a gay man suffered an aneurysm and his parents subsequently became his legal guardians, immediately preventing his long-time boyfriend, with whom he had lived prior to his hospitalization, from visiting him because they disapproved of the relationship. The court upheld the right of the parents to prevent the men from even seeing each other, saying that "Patrick's parents had the ultimate and sole responsibility . . . to determine and control visitation with and access of visitors to Patrick Atkins in his best interest."[275]

Similarly, a lawyer who was interviewed for this project recalled several cases in which guardianship was sought for the expressed purpose of preventing the individual subject to guardianship from having an intimate relationship of which the guardian did not approve. In one case, a mother had sought and obtained guardianship over her 19-year-old daughter who was deaf and had some emotional problems in order to prevent her from seeing her somewhat older girlfriend. In another case, a father sought guardianship over his young adult daughter with a mild cognitive impairment because she had created a profile on a dating website. In his order, the judge specifically noted that this behavior on her part opened the door to sexual exploitation and a guardianship was necessary to protect her. The father's motives in this case might be understandable, but in an era when 27 percent of adults ages 18 to 24 use online dating websites, the conclusion that seeking companionship through an online dating profile opened the door to exploitation should be questionable at best, especially as legal grounds for guardianship.[276]

One can clearly recognize and understand the consequences of failing to protect an individual subject to guardianship from sexual exploitation or abuse. However, there is also harm in preventing individuals who are subject to guardianship from having an outlet for sexual expression, which the Supreme Court has recognized as being "[a]t the heart of liberty . . . ."[277] This right is as important to individuals subject to guardianship as it is to everyone else, even if it makes some uncomfortable or uneasy.[278] Although "the degree to which [the right] extends to people who have cognitive impairments remains unexplored,"[279] there can be no doubt that exercising control over another human being's opportunities for sexual expression implicates an important liberty interest.

[T]here is also harm in preventing individuals who are subject to guardianship from having an outlet for sexual expression, which the Supreme Court has recognized as being "[a]t the heart of liberty . . . ."

The National Guardianship Association (NGA) has taken an important step in asserting that guardians should recognize the right of individuals subject to guardianship to engage in sexual expression and take steps to ensure that such sexual expression is consensual. Additionally, NGA has made information available to professional and family guardians at its annual conferences and on its website that can help

guide these discussions and help guardians make good decisions with respect to these issues.[280] However, taking these steps alone may still prove insufficient to protect an individual from having his or her sexual autonomy essentially revoked while subject to guardianship. As discussed in Chapter 8, the process of supported decision making might be a more effective way of ensuring that people subject to guardianship or who need decision making assistance are not completely deprived of a right to sexual expression.

Jurisdictional Issues

Because guardianships are created under state law, a host of vexing problems can arise that have to do with which state has jurisdiction over an individual who is alleged to be incapacitated or who is subject to guardianship. For example, what state has jurisdiction over an individual subject to guardianship who is receiving treatment in a specialized facility in another state? Can a state such as Florida impose a guardianship on an individual who is a snow-bird and only lives in the state during the winter months? Is a relative who lives in a different state than an individual subject to guardianship a more appropriate choice as a guardian than a professional or public guardian within the state? As Sally Balch Hurme, a prolific author on issues related to guardianship and aging, has pointed out, "guardianship has been traditionally 'strictly local.' But in today's mobile society, it is difficult to contain guardianship issues within one state's boundaries."[281]

"[G]uardianship has been traditionally 'strictly local.' But in today's mobile society, it is difficult to contain guardianship issues within one state's boundaries."

The Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGPPJA) is a uniform law that has been adopted in all but three states (Florida, Texas, and Kansas) and helps clarify which state's laws govern particular situations within guardianship cases.[282] The UAGPPJA provides a number of advantages:

- Provides a clear process for identifying which state may appoint a guardian for an adult who has homes in multiple states
- Facilitates the transfer of guardianships when a guardian and person subject to guardianship move from one state to another
- Enhances interstate recognition and enforcement of out-of-state guardianship orders, enabling a guardian to act in multiple states if necessary (e.g., to sell property in state B even though the person subject to guardianship lives in state A)
- Provides a simplified process for courts to communicate and cooperate with each other, making it easier for courts and parties to communicate, maintain records, and respond to requests
- Provides for emergency appointment of a guardian when a person subject to guardianship is or who is allegedly incapacitated is in a state but does not live there

The act clarifies the rights and responsibilities of states and parties in guardianship cases that cross state lines, which can help ensure greater due process for individuals subject to

guardianship and save resources for families. Additionally, the law puts in place procedures that allow courts to take jurisdiction over individuals who were brought to a state through "unjustifiable conduct" or for the purposes of exploitation. The ABA collected stories of multistate guardianship issues from 2008 through 2009 that vividly detail how the UAGPPJA improves the way guardianships function across state lines. However, there may still be situations where the UAGPPJA does not provide all the answers. The goal of the UAGPPJA is in large part to allow for the easy transfer of cases from one state to another when a person with a disability moves across state lines. However, there have been well-documented problems with specialty care facilities that advertise their services across state lines to guardians who then send individuals to the facility for treatment. In some cases, there have been allegations that the facilities are not providing the best care, but the out-of-state guardian is not readily able to ascertain the problems or visit the individual regularly, and the individual may not have access to the courts in their home state or in the state where the facility is located. In that case, transferring the guardianship to the state where the facility is located could jeopardize the person's eligibility for important sources of financial support such as Medicaid waiver, state-based trust funds (e.g., for people with head injury), and worker's compensation. Additionally, a local court taking over the case of an individual who ultimately wants to and should return to their home state where they may have better natural supports may actually make it harder for the person to achieve that goal.[283] These issues were examined in a Congressional hearing in 1992.[284] However, according to a series of reports from the Center for Investigative Reporting, the problem continues unabated.[285]

[T]ransferring the guardianship to the state where the facility is located could jeopardize the person's eligibility for important sources of financial support such as Medicaid waiver, state-based trust funds . . ., and worker's compensation.

Restoration of Rights

As outlined throughout the report, there are three instances in which a review for the possible restoration of rights is in order:

- When guardianship is imposed and the individual did not meet the legal standard of incapacity
- When the individual did meet the definition of incapacity but a less restrictive alternative than guardianship would have provided sufficient assistance and protection
- When an individual subject to guardianship regains capacity either due to a medical recovery or because he or she has acquired the necessary knowledge and skills to make and implement decisions

When any of these situations occur, there must be a way to restore the rights of a person subject to guardianship. Perhaps not surprisingly, although each state provides for means to terminate a guardianship and restore one's rights, there is little data on the frequency of or circumstances under which such restorations

Circumstances Warranting a Review and Possible Restoration of Rights

- When guardianship is imposed and the individual did not meet the legal standard of incapacity
- When the individual did meet the definition of incapacity but a less restrictive alternative than guardianship would have provided sufficient assistance and protection
- When an individual subject to guardianship regains capacity either due to a medical recovery or because he or she has acquired the necessary knowledge and skills to make and implement decisions

occur. One of the individuals subject to guardianship who was interviewed for this report summarized the difficulty she encountered in terminating guardianship: "I had to prove myself over and over, and over again for like six months straight that I can budget my money and all that stuff and they finally gave me my rights back. . . . it took three years to get my rights back."

ABA Commission on Law and Aging/ Virginia Tech Center for Gerontology Study

Although the lack of reliable data limits analysis, a 2017 study conducted by the ABA Commission on Law and Aging in conjunction with the Virginia Tech Center for Gerontology sheds some light.[286] Since this is the only report of its kind, this section will rely heavily on this report and its findings. Therefore, throughout this section, it will simply be referred to as the *ABA Restoration Report* or *study* for clarity.

The authors of the *ABA Restoration Report* identified and examined each state's statutes and procedures governing restoration, and analyzed reported cases going back to 1845, with a particular focus on 57 cases since 1984. An interdisciplinary roundtable of experts in guardianship, aging, and disability—including NCD staff—was convened to develop the findings and recommendations in the report. Even though the report's findings are interesting, many questions are left unanswered due to limitations in available data.

Only four states could provide data on restoration cases at the probate court level, for a total of 275 restoration cases:

- Of those 275 cases, 80 percent involved individuals who were age 17 to 59; more than 65 percent lived in their own home or the home of their family; and 70 percent had estates of less than $50,000.
- In approximately 33 percent of the cases, the reason for guardianship was mental illness, in approximately twenty percent of the cases the individual had an intellectual disability, and only a small number of cases involved people with dementia.
- In almost 75 percent of the cases, the guardianship was over both person and property.

Eighty-four of the cases were pulled from public guardianship files, and were therefore excluded from data calculations because these cases all involved guardianships with common characteristics (e.g., minimal assets and income, nonfamily guardian) that would throw off the

analysis of variables the study was attempting to understand. However, from the remaining court files, family guardians were appointed 68 percent of the time, and private professional guardians or private for-profit guardianship agencies were guardians 24 percent of the time.

It's encouraging that in 40 percent of the cases, the petitioner who was seeking to have the individual's rights restored was the guardian, and often a family member. In almost as many cases, the petitioner was the individual subject to guardianship. The report also notes that the vast majority of these cases are "uncontested," meaning that no one opposes the assertion that the person should get his or her rights back—at least not as an official matter of record with the court. Additionally, in approximately 42 percent of the cases, the individual subject to guardianship was not represented by a lawyer, but since most were uncontested cases, it is perhaps not surprising that they were nonetheless successful. It's difficult to draw many conclusions from the data because it did not include cases where restoration petitions were filed but not granted. North Carolina did, however, provide the dispositions of 223 cases from 2010 through 2015. Still, among the North Carolina cases about three-quarters were successful.

The authors of the study note that:

> . . . the court file research produced a snapshot of a "successful restoration case" across states. In this typical case, the individual is about 40 years old, lives at home, has an estate under $50,000, and has a mental illness or perhaps a dual diagnosis with other conditions. The guardian is most likely a family member. After two to five years, the individual is restored, and his or her rights are returned. Either the family guardian or the individual himself or herself petitions for the restoration, and it is the first attempt. The case is not contested. The individual has no legal representation—or may have a court-appointed attorney or guardian ad litem. The case is built on a combination of clinical and lay evidence. The court restores all rights without any particular terms.[287]

The authors conclude that these cases show that the restoration process can work, but that there might be many cases in which a petition is never filed because the person, his or her guardian, or his or her family does not know that the person is entitled to seek restoration. Additionally, it was noted by some at the roundtable that there might be many cases in which the person indicates to the court that he or she would like his or her rights back but receives no response; or in which the persons asks his or her guardian for help with the process and is denied. Finally, there might be many more cases in which rights are not restored because the guardian or another person contests the petition for restoration, essentially operating as the opposing party. Far less is known about these cases and their disposition.

State Laws Vary on Restoration

The statutes in each state vary widely in key aspects of the restoration process, and as in other areas of guardianship, vary in practice from the process prescribed in statute. In the roundtable discussions, participants identified potential issues that impact the likelihood that a person subject to guardianship will have their rights restored to include the following:

- Awareness of restoration as an option
- Access to the courts

Issues Impacting the Likelihood of Restoration of Rights

- Awareness of restoration as an option
- Access to the courts
- Periodic court review of the continuing need for guardianship
- The right to counsel (and the role of appointed counsel as zealous advocate and not guardian ad litem)
- The role of the guardian in restoration cases
- The focus on supports and alternatives to guardianship
- Evidentiary standards

- Periodic court review of the continuing need for guardianship
- The right to counsel (and the role of appointed counsel as zealous advocate and not guardian ad litem)
- The role of the guardian in restoration cases
- The focus on supports and alternatives to guardianship
- Evidentiary standards

Some of these issues are addressed in the revised Uniform Act (UGCOPAA), which provides that within 14 days of appointment of a guardian, the individual and other named parties (generally family and the guardian) must receive notice of their right to seek restoration.

In addition, four states already have a "bill of rights" for individuals subject to guardianship that specifically enumerate the right to seek restoration. The revised act also requires guardians to submit annual reports that, among other things, include recommendations regarding the continued need for guardianship and whether any of the individual's rights should be restored. For example, Tex. Estates Code § 1101.103 requires a physician's certificate to state whether improved functioning is possible and to state the time-frame for reevaluation.

In recognition of the fact that individuals subject to guardianship might not have the means or know-how to file a petition to have their rights restored, 20 state statutes and the revised act permit informal requests such as handwritten notes or verbal requests by an individual asking to have their rights restored. However, there is no way to know how effective these communications are, and some roundtable participants expressed concern that such requests sometimes are ignored and do not lead to formal restoration proceedings. The study does note that there were several examples of this approach being successful in the case files.

20 state statutes and the revised act permit informal requests such as handwritten notes or verbal requests by an individual asking to have their rights restored.

The Role of Guardians in Restoration Cases

The role of the guardian in restoration cases can also be problematic. The report notes that ". . . it appears that the guardian's opposition may have negatively affected the disposition, as only 33 percent of petitions were successful when the guardian opposed the petition, but 50 percent

were successful when the guardian was in support."[288] Some view guardian opposition to restoration petitions as a conflict of interest, especially since the estate of the individual subject to guardianship will pay for any of the activities taken in opposition to the petition. The cost of seeking restoration can be prohibitive, although some states are in the processes of amending their statutes and practices to make it less expensive. After an appellate court in Colorado concluded that a guardian can oppose a motion by the person subject to guardianship and can charge the estate of the person for doing so, the Colorado legislature revised the guardianship statute and prevented guardians from opposing or interfering with a petition for restoration sought by the individual. However, the situation highlighted by the Colorado case continues to be a problem in other states.
The case law review of the report identified several cases in which the court ordered the payment of the attorney's fees of the guardian out of the estate of the person subject to guardianship, leading the authors of the report to conclude, "it appears that an individual subject to guardianship may need to not only battle the fiduciary who is appointed to act on the person's behalf, but also pay steeply for it."[289] However, some at the roundtable felt that there were circumstances under which a guardian may reasonably have a good faith belief that the person continues to benefit from guardianship, ". . . and continuing protection is needed against exploitation or undue influence."[290]

Attorneys in Restoration Cases

Another related issue is the individual's right to an attorney in restoration cases and the role of the attorney. The revised Uniform Act and 18 states require the same procedural safeguards that apply when guardianship is first sought. Twelve state statutes require the appointment of counsel when an individual subject to guardianship seeks restoration of rights. However, as with representation on the "front-end" of guardianship, the role of counsel in these cases is not always clear. As noted earlier in this report, the ABA Model Rules of Professional Conduct Rule 1.14 call for the lawyer to act in the traditional advocacy role of an attorney for his or her client even when the client has diminished capacity, unless the lawyer feels that there is a substantial risk of harm to the client. This leaves open the possibility that the attorney will independently determine that the individual continues to need a guardian and fail to advocate for his or her client's wish to have rights restored. This may spring from misguided paternalism or a genuine concern for the health and safety of the client. Regardless of the reason, the result is that the individual does not have effective counsel advocating for the individual's desired outcome. Furthermore, in the experience of some of the individuals at the roundtable, the attorney who represented the client in the original guardianship proceeding is often appointed to represent the individual when seeking to restore rights. That attorney may or may not have advocated against the guardianship in the first place and is certainly unlikely to raise arguments that are based on evidence that his or her client was erroneously determined to lack capacity in the first place.

The Restoration Report raises the question of whether legal services or Protection and Advocacy Attorneys are representing individuals seeking to have their rights restored. The report's case file research revealed that legal services attorneys represented individuals in

only a couple of cases, and Protection and Advocacy (P&A) attorneys did not play a role in any of the cases examined. This result was somewhat discouraging given that the P&As are federally funded to provide legal and advocacy services for people with a variety of disabilities, so you might expect them to play a role in the restoration of the civil rights of individuals subject to guardianship. However, "A 2017 report by the National Disability Rights Network (NDRN) found that 84 percent of the 50 P&A agencies responding to a survey currently represent or could represent [people] with disabilities in guardianship issues."[291] The NDRN report goes on to note that when P&As get involved in guardianship cases, it is usually to help an individual with full or partial restoration of rights. One attorney with experience working as a P&A attorney in restoration cases who participated in the roundtable reported that, in order to get the court to allow her to represent clients for whom she had filed a restoration of capacity instead of the court-appointed attorney, she would regularly file an affidavit indicating that her client would not be charged for her services regardless of the outcome. Ironically, in several cases she reported that the guardian and his or her attorney were regularly paid out of the estate to oppose the petition for restoration. Additionally, in one case, the court effectively made the original attorney co-counsel, although he subsequently appeared as a witness and testified that the individual subject to guardianship continued to need a guardian. The individual's rights were fully restored after several hearings, but not before the attorney who testified against the petition was paid out of the estate of the individual.

While it is a positive development that P&A attorneys are getting involved in guardianship cases in recognition of guardianship as a critical civil rights issue for people with disabilities, the payment mechanisms are problematic when a publicly funded attorney is put in the position of representing a client whose money will be used to pay their opposing counsel. Given the limited availability of funding for P&As and legal services, it's common practice for attorneys in those organizations to try to recoup attorney fees from the opposing party (often the state) when they are successful. However, in guardianship cases, the only person paying for anything is often the person who is subject to guardianship, although in a few instances when the individual is indigent and the state, county, court, or other mechanism is used to pay the court costs and other fees. In most cases, unless there is proof that the guardianship was filed in bad faith or some other malfeasance occurred in the course of the guardianship, there is no one to recover from other than the individual subject to guardianship. Since P&As do not charge their clients for the services they provide, they would not be able to recoup fees and costs from the individual. Restoration cases can be very complex and time consuming, and the costs can be considerable—especially if they have to hire, and pay for, an independent expert to refute the testimony of the court-appointed expert. Under the circumstances, it's actually surprising

[T]he payment mechanisms are problematic when a publicly funded attorney is put in the position of representing a client whose money will be used to pay their opposing counsel.

that P&As and legal services are willing to take these cases at all, but according to the NDRN report, many of them are. Finally, many P&As provide information to people with disabilities and their families regarding guardianship, including their right to have the need for guardianship reviewed and about the availability of alternatives. For example, the Kentucky P&A makes these resources available on their website.[292]

Evidentiary Standard/Burden of Proof

The evidentiary standard and burden of proof could also impact the success of restoration cases. According to the report, 34 jurisdictions fail to outline an evidentiary standard in statute, "leaving wide discretion for courts and uncertainty for litigants."[293] Only two states, the UGPPA, and the revised Act make it clear that all the petitioner has to establish is a prima facie case for restoration unless the opposing party submits clear and convincing evidence that the guardianship should continue. Eight states require the petitioner to prove that there is clear and convincing evidence that the person should have their rights restored, and in seven states the petitioner must meet a preponderance of the evidence standard. Mississippi leaves the decision entirely up to the judge, requiring "such proof as the chancellor may deem sufficient."[294] This lack of clear standards creates a very difficult environment for attorneys who rely on evidentiary standards not only to plan and build their case, but also to make decisions about their likelihood of success. This uncertainty unfairly prejudices the rights of individuals subject to guardianship.

Many state standards also remain unclear whether restoration is appropriate only when an individual's capacity has been established legally, or if restoration might also be appropriate in instances in which, although the individual still meets the legal definition of *incapacitated*, a less restrictive alternative such as supported decision making is either in place or could be if the guardianship is dissolved. The recent *Ross v. Hatch* case in Virginia and *In the Matter of the Guardianship of Dameris L.* in New York, and in the 1995 case *Hedin v. Gonzalez* from Iowa stand for the proposition that guardianship may be removed if sufficient supports are in place, even if the person still meets the definition of *incapacitated* according to the state statute.

The evidentiary standard and burden of proof could also impact the success of restoration cases. According to the report, 34 jurisdictions fail to outline an evidentiary standard in statute . . .

Restrictions on Restoration Efforts

Because guardianship represents a very serious curtailment of a person's liberty, it is of the utmost importance that individuals subject to guardianship be given a real opportunity to seek to have their rights restored when that becomes appropriate. However, as noted earlier, the burden of paying for restoration or even attempts at restoration generally fall on the person seeking to have his or her rights restored. Since preserving the individual's assets is one of the primary purposes of guardianship, it's perhaps not surprising that a few states curtail the ability of petitioners to file petitions for restoration of capacity. In all, 17 states either require or allow courts to specify that a petition for restoration

may not be filed within a given time-frame, not to exceed one year. In a few additional states, the statute provides that a petition for restoration cannot be filed within six months after an attempt at restoration has failed.[295]

While, regrettably, these restrictions have a chilling effect on individuals attempting to file for restoration of rights, they could be necessary to protect the resources of individuals who may file numerous futile and ill-conceived petitions for restoration, sometimes influenced to do so by individuals seeking to exploit them. However, within these limitations, individuals who are subject to guardianship must have access to the courts so that the guardianship can be removed and rights restored at the earliest possible opportunity, whether it's because the decision to impose a guardianship in the first place is called into question, the individual's condition has improved, the person's functional abilities developed or have been regained, or supports and services have been identified that alleviate the need for guardianship. The authors of the restoration report note that data on the frequency of restoration is almost nonexistent, but it seems to be a rare occurrence. This raises the very real possibility that a large number of people continue to be subject to guardianship even though they have developed skills and alternatives that might allow them greater independence.

As we have noted throughout this report, continuation of the deprivation of one's self-determination through the vehicle of guardianship is a violation of one's basic civil rights and liberties unless no less restrictive alternative can be found. When an individual subject to guardianship is willing to reach out and ask the court to restore their rights, that, in and of itself, is a clear indication that the individual is keenly aware that he or she has lost something important that is worthy of pursuing restoration of, and the court systems and state laws should work in such a way as to welcome ready review of whether a guardianship remains justifiable and appropriate.

Chapter 8: Less-Restrictive Alternatives to Guardianship

Throughout this report, NCD has noted that guardianship law has evolved significantly over the past three decades. However, guardianship law, despite its reforms, has not kept pace with advances in civil rights over the past 40 years and remains a system that would be recognizable to the ancient Greeks. With that in mind, guardianship is not the only way to address some of the difficult issues that arise when a person's disability or age raises questions about his or her ability to make decisions concerning health and welfare or to manage his or her property.

Olmstead Necessitates Finding Alternatives to Guardianship

In 1999, in the *Olmstead* decision, the U.S. Supreme Court interpreted the ADA to give rise to an obligation to provide services to people with disabilities in the least restrictive environment that will meet their needs.[296] Such rights do not disappear when an individual becomes subject to guardianship. As one guardianship professional interviewed for this report concluded, "It is the responsibility of the guardian to make sure that those rights of the individual are honored and respected." Both within and outside of the guardianship context, many advocates, scholars, and legal experts are considering ways to better integrate people with disabilities into the decision making process. Leslie Salzman, a law professor who is perhaps best known for advancing the proposition that guardianship can constitute a violation of the ADA's integration mandate, has called for society to radically rethink guardianship and the whole idea of surrogate decision making:

> Rather than focusing on how to improve the guardianship process, we will consider innovative ways to integrate [people] with diminished mental capabilities to the greatest extent possible into the management of their personal and property affairs. With the appropriate level of decision-making support, [people] with disabilities will be further integrated into the "theater" of human activity and guardianship will rarely be needed and will be utilized in only the most extreme circumstances.[297]

Introduction to Alternatives

Guardianship statutes, for the most part, already require courts to look to less-restrictive alternatives before imposing a guardianship. These alternatives may be informal or formal and may themselves be restrictive. NCD's research found that guardianship can be at odds with the goals of promoting the self-determination of

people with disabilities, is fraught with constitutional issues, and potentially exposes people with disabilities to exploitation; this necessitates an analysis of alternatives to guardianship. This report is not intended to describe all of the alternatives in detail, but these alternatives are important steps in the path forward for people with disabilities who need or want decision making assistance and the people who care about them.

Each of the following alternatives offers slightly different solutions that can be modified to fit the circumstances of the individual and the people in their lives. What is more important than the particular method of decision making assistance is one's commitment to understanding and incorporating the wishes and needs of the person into the decision making process, rather than focusing solely on protection. The primary alternative to guardianship should always be self-directed decision making—sometimes called *supported decision making*—which encourages individuals to access whatever advice and counsel they're comfortable with from family, friends, and professionals with whom they are in relationships of trust. However, some individuals may want or need more formal arrangements in order to implement the types of daily decisions that we all make in our lives. The circumstances of the individual, including their wishes, needs, resources, and availability of trustworthy support networks should be considered when considering alternatives to guardianship.

As has been pointed out again and again throughout this report, people make bad, ill-informed decisions all the time—and some of those people have disabilities and others do not. What is clear is that some individuals need or want assistance with decision making, and they should be able to readily access effective and meaningful alternatives to guardianship that enhance, rather than undermine, their self-determination.

Although supported decision making has received a great deal of recent attention as an alternative, there are many other alternatives that have been used in lieu of guardianship for a long time, and many of them are also used in conjunction with supported decision making. Determining when an alternative to guardianship is appropriate and which one to use for which kind of circumstance or decision is no more of an exact science than determining when an individual lacks capacity and needs a guardian. As discussed in the following section, each of these alternatives carries with it the potential for misuse. However, if this report has shown anything it is that guardianship does not always offer the level of protection against abuse and exploitation that it is intended to, and the protection that it offers comes at a high price to the freedom of the individual subject to guardianship. As we move away from relying on

NCD's research found that guardianship can be at odds with the goals of promoting . . . self-determination . . ., is fraught with constitutional issues, and potentially exposes people with disabilities to exploitation; this necessitates an analysis of alternatives to guardianship.

guardianship and focus on assisting individuals with decision making rather than supplanting it, policymakers will need to explore innovative ways to prevent abuse while advancing self-determination.

This chapter will first discuss a model that has been developed by the ABA to help decide what decision making assistance a person may need. This is followed by a brief exploration of the most commonly used alternatives to guardianship and by a more extensive examination of supported decision making, which is emerging as the most promising and comprehensive alternative to guardianship.

A Practical Tool for Considering Alternatives

Four sections of the ABA, with the assistance of the National Resource Center for Supported Decision-Making, designed the "PRACTICAL" tool to assist lawyers in identifying less restrictive alternatives to guardianships. The name of this tool is an acronym that comes from the nine-step process described following this paragraph. The tool is useful for attorneys advocating on behalf of a client facing guardianship, representing families who are thinking about seeking guardianship, serving as guardians ad litem, and serving as guardians or representing guardians who are considering whether rights restoration may be appropriate given the availability of existing alternatives.

The PRACTICAL tool holds a great deal of promise for changing the way that lawyers think about their obligation to protect people with diminished capacity. Such a no-nonsense approach has the potential to operationalize finding alternatives to guardianship and to divert some would-be guardianships into less-restrictive alternatives. At the very least, using this tool provides a layer of assurance that alternatives to guardianship have been thoroughly considered and decreases the likelihood that an individual will end up in an unnecessary guardianship that unnecessarily curtails their liberty to make decisions for themselves.

PRACTICAL Steps to Identify Less Restrictive Alternatives to Guardianships

The steps in the PRACTICAL process are as follows:[298]

1. **Presume** guardianship is unnecessary. This step encourages the lawyer to assume at the outset that there may be less restrictive alternatives that can address the individual's need.
2. **Reason.** This step encourages the lawyer to consider the reason that there are concerns about the individual's ability to make decisions.
3. **Ask** whether the concern may be caused by a temporary or reversible condition. This step encourages lawyers to screen for conditions or environmental factors that may be affecting decision making ability, but which could be mitigated or reversed, alleviating the need for guardianship.

(continued)

PRACTICAL Steps to Identify Less Restrictive Alternatives to Guardianships, *continued*

4. **Community.** This step encourages the lawyer to determine whether the concerns can be addressed by connecting the individual to family or community resources that can provide support and alleviate the need for guardianship.
5. **Team.** This step encourages the lawyer to ask whether there is or could be a "team" in place that could assist with decision making and helps them identify potential supporters.
6. **Identify** abilities. This step encourages the lawyer to recognize that the person may need assistance in some areas but have strengths in others areas. This step may include getting an evaluation by a professional or using the existing capacity handbook for lawyers discussed in Chapter 5.
7. **Challenges.** This step encourages the lawyer to screen for potential challenges with the identified supports and supporters. Avoiding guardianship is not helpful if the alternative is not viable on a long-term basis or exposes the individual to potential abuse, neglect, or exploitation by putative supporters.
8. **Appoint.** This step encourages the lawyer to examine whether the person is able to appoint a legal surrogate. In such cases, the lawyer should explore ways to establish powers of attorney and health care surrogates and identify other documents that can help supporters implement decisions consistent with the individual's values and preferences.
9. **Limit.** If there are areas where no less restrictive alternatives to guardianship can meet the individual's needs, it may be necessary to move forward with a guardianship petition. This step encourages the lawyer to work to make sure the resulting order is as limited in scope as it can be.

Alternatives by Context

Financial Decisions

A recurring concern expressed in the interviews conducted for this report was the ability of some individuals to manage money and use their available and often limited resources effectively to make sure that they are able to take care of their basic necessities such as food, clothing, and shelter. The complexity of these issues varies considerably based on the type and amount of available resources an individual has. A young person with intellectual disabilities whose only monthly income comes from SSI benefits administered by the SSA will have different needs for assistance with money management than a retired person with dementia who has a sizable retirement account or pension—even though their cognitive functioning and comprehension of money management may be equally impaired. Accordingly, the options that are available may vary as well. Additionally, the source of the income will impact which alternative to guardianship is available and most appropriate.

Banking Options

One possibility that would likely be available in a broad range of circumstances falls under the general rubric of "banking options." Online banking has flourished in the past decade or so and has fundamentally changed how we all use and manage money. According to the 2016 U.S. Consumer Payment Study, only 11 percent of Americans prefer cash over debit or credit cards for most purchases, with 40 percent of Americans preferring to use credit and 35 percent preferring to use debit cards.[299] According to the study, more and more Americans are paying bills online and through automatic payments and the majority of consumers use a debit or credit card to pay recurring bills while only 14 percent write monthly checks to pay recurring bills such as rent, gas, electricity, and cable. Along these same lines, the way we interact with banks has changed. In 2016, the majority of respondents indicated that they used a mobile banking app. This shift has impacted our economy on a macro level, but it also means that—on a micro level—fewer and fewer of us regularly go into a bank to make transactions. In fact, on March 1, 2013, the treasury department stopped issuing paper Social Security checks in favor of direct deposit. From a practical standpoint, this means that many of the same people from the disability and aging populations who may be seen as lacking capacity and needing a guardian currently or will have bank accounts or prepaid debit card accounts into which their checks can be deposited. These individuals could potentially get assistance from someone they trust to help them with their banking and bill paying using a computer or mobile device. That being said, it is also true that the Federal Deposit Insurance Corporation (FDIC) found in a nationwide survey conducted with the

National Disability Institute (NDI) that people with disabilities were far more likely to be considered "unbanked" because no one in their household had either a checking or savings account. Since the definition of disability that NDI used in their survey includes many individuals who would not meet the strict definition of disability used by the SSA, it's not clear what, if any, impact the 2013 law has had on the number of "unbanked" people with disabilities.[300]

Online banking and bill paying using a mobile app make it easier to get assistance with managing money, and, although they may create the potential for exploitation, the Federal Government is taking steps to address this possibility. In 2013, the Federal Reserve, the Consumer Financial Protection Bureau, the Securities and Exchange Commission, and five other Federal Government oversight bodies issued interagency guidance for banks on reporting financial abuse of older adults.[301]

This guidance clarifies the important role banks can play in curbing financial abuse and highlights previously published guidance describing suspicious activity such as unusually large withdrawals, closing of certificates of deposit and accounts without regard to penalties, and debit transactions that are out of character or inconsistent with prior transactions.[302]

Other alternatives for managing money and property for people with disabilities who may need assistance in doing so include powers of attorney, special needs trusts, and appointment of a representative payee for Social Security benefits, which will be discussed in the pages that follow. Each should be considered carefully as they restrict the person's access to their own resources and, while less restrictive than guardianship, may suffer from some of the same infirmities.

Powers 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. We often think of a power of attorney in terms of financial or health care decision making, but it can be a useful legal instrument in a variety of contexts. A power of attorney is "durable" when the document indicates that the agent's authority does not end if the person becomes incapacitated. A "springing" power of attorney only becomes effective once a certain event occurs, such as the principal becoming incapacitated, but is a type of power of attorney that is not legally recognized in some states. Although forms are often available online, powers of attorney are powerful documents that require careful consideration by the principal, who may benefit from a lawyer's advice and drafting experience, particularly in the area of finances. To be valid, powers of attorney must conform to state law requirements, some of which include notarization and witnessing.

The primary advantage of powers of attorney is that they are low cost and easy to create, change, and revoke. Powers of attorney have been used as an alternative to guardianship for older adults for a very long time; these legal instruments give people the opportunity to decide who they want to assist them as they grow older and to have meaningful conversations about important life decisions, such as long-term care and management of their property as their needs change. As one professional working in elder law who was interviewed for this report noted, powers of attorney can—assuming they are drafted well and a trustworthy agent is appointed—completely take the place of guardianship of the property.

The primary advantage of powers of attorney is that they are low cost and easy to create, change, and revoke.

Despite misconceptions to the contrary, many people with cognitive or intellectual disabilities also can execute powers of attorney and advance directives for health care. [303] More public education, particularly of the legal and judiciary communities, needs to be done to ensure that this legal tool—an important civil right under state law—is equally available to people with cognitive or intellectual disabilities who can knowingly and voluntarily use it. As one professional NCD interviewee stated, "We have to create education with the public [and] with judges, so that the signatures of people with

disabilities will be [honored]. I think that third party [recognition] remains . . . an issue."

As is the case with guardianship, alternatives to guardianship, including powers of attorney, can be used exploitatively. The concerns include whether or not the appointed agent will follow the wishes of the person and act ethically and diligently and whether or not the lack of court supervision may put the person's safety or financial well-being at risk. These concerns are not unjustified, examples of physical, emotional, and financial abuse by agents, including family members, are not difficult to find. Some have even characterized the durable power of attorney for property is "a license to steal."[304] As a result, financial institutions can be very cautious about honoring powers of attorney, which can result in them being less effective. Powers of attorney are only as protective as the agent is trustworthy, only as effective as the willingness of third parties to accept it, and—like guardianship—do not prevent things like family power struggles over the person or his or her assets.[305]

Many debate what statutory reforms are needed to add safeguards to the use of powers of attorneys. Recent suggestions have included requiring 1) all durable powers to follow a standard statutory form with protective language (e.g., such as that within the Uniform Power of Attorney Act); 2) all durable powers to be registered with an oversight agency to be effective; 3) notice to be given to family members of such registration; and 4) increased court or governmental oversight that allows investigations if suspected abuse is reported.[306] Although these reforms are worthy of consideration, the historical unwillingness to devote greater resources to monitor and prevent abuses in guardianship suggests that there may be a similar unwillingness to devote public resources to monitor and enforce the terms of what are essentially private agreements among parties. In the end, powers of attorney are an important alternative to guardianship that gives the individual greater ability to decide who should help them make and carry out decisions and to revoke that decision if they so choose. Although there is risk of abuse with powers of attorney, guardianships also carry these risks, despite their intention to prevent it.

Trusts and Special Needs Trusts

A trust is a legal relationship wherein a person has a legal obligation to manage property—such as money, real property (land), personal property (such as jewelry), or anything else of value—for the benefit of another person.[307] A special needs trust is a particular kind of trust that can be established for the benefit of a person with a disability.[308] 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. Although the trustee and the beneficiary can be the same person, in situations where the goal of the trust is to manage money for a beneficiary who may need assistance, the trustee would usually be a trusted family member, friend, or professional.[309]

A trust can offer some of the same benefits of guardianship in the sense that the beneficiary cannot directly access the resources, which are therefore protected from waste and third party influence or exploitation. Additionally,

trustees are obligated to comply with rules that govern fiduciary responsibility and can be legally responsible for mismanagement, which provides a layer of accountability and formality that may work well as an alternative to guardianship for some.[310] On the other hand, a beneficiary of a trust has limited recourse if he or she disagrees with the way the trustee is spending the money. For example, a beneficiary might want the money in a trust used to buy something that seems objectively reasonable, such as a new television. However, if the trustee disagrees and refuses to buy that item, there is little the beneficiary can do, provided that trustee is otherwise spending or saving the money in a prudent manner for the beneficiary's benefit. In that sense, a trust can limit the individual's self-determination as much as a guardianship of the property.

[A] beneficiary of a trust has limited recourse if he or she disagrees with the way the trustee is spending the money.

Representative Payee

In the Social Security benefits context, a representative payee is a person or an organization appointed by the SSA 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. The representative payee is also accountable to SSA for how the money is spent and must be able to report this information to SSA.

[T]he representative payee program may be an alternative to guardianship that suffers from many of the same problems that are prevalent in guardianship systems.

A representative payee can play an important role in ensuring that benefits are spent wisely and that they are used to support the beneficiary's needs. However, SSA has faced criticism for failing to appropriately screen and monitor representative payees and for failing to recruit suitable payees for individuals who do not have family or friends available to assist them.[311] Additionally, the determination of who needs a representative payee has been called ". . . less than scientific . . ." by former SSA Inspector General Patrick O'Carroll.[312] In other words, the representative payee program may be an alternative to guardianship that suffers from many of the same problems that are prevalent in guardianship systems.

Health Care Decisions

Guardianship is sometimes sought because an individual is thought to be unable to make medical decisions for themselves. Often, this is because a physician or other medical professional does not feel that they can obtain "informed consent" from the person to proceed with a medical treatment, procedure, or even examination. The medical provider must be sure the patient understands the purpose, benefits, and risks of a procedure, as well as the range of treatment options, and voluntarily consents to the procedure. If the medical provider does not do so, any therapy or treatment ". . . may amount to a tort—a common law battery—by the physician."[313] If

the provider does not believe the patient is capable of providing informed and voluntary consent, they may require the appointment of a substitute health care decision maker, which may in turn raise various issues depending on the age of the patient, his or her health condition (particularly if it involves reproduction or a terminal condition), and his or her relationship to the people who might naturally be available to assist with medical decisions. Parents of young adults with intellectual and developmental disabilities are often counseled to obtain guardianship lest they be shut out of their child's medical decision making or—worse—their child be unable to access medical care. However, these fears are frequently unfounded, given the number of viable alternatives usually available in the health care context.

HIPAA

Under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), a patient can voluntarily authorize disclosure of otherwise protected and confidential health information to whomever they choose, including his or her parents and other family members. If the patient is not present or is incapacitated, a health care provider can disclose information if it is in the best interest of a patient to do so. HIPAA does allow a person, including adults with disabilities, to specifically prevent disclosure of their private information, as long as they have capacity.[314] However, this should not necessarily be viewed as problematic. While we may care about loved ones and want the best for them, the purpose of HIPAA is to give individuals the autonomy to decide whom they trust to assist with health care decisions.[315]

Advance Directives

Even if a doctor does not believe that the individual has capacity to make health care decisions and therefore cannot provide informed consent, with appropriate planning, guardianship can still be unnecessary. Advance planning tools, such as advance directives, can be used to memorialize the individual's health care preferences. Advance directives detail the person's preferences with respect to certain medical interventions should they become unable to communicate them to a doctor. Most states also allow individuals to designate someone as their surrogate to make decisions for them in the event they become incapacitated and cannot make medical decisions for themselves. These tools are often most useful in the context of end-of-life decisions and are dependent on the person having capacity when they sign the document. There has been debate around exactly what level of capacity is required in order for an individual to legally execute an advance directive or health care proxy, and the answer will depend on state law and legal precedent.[316]

Advance directives detail the person's preferences with respect to certain medical interventions should they become unable to communicate them to a doctor.

Surrogate Health Care Decision Making Laws

Even in circumstances in which individuals have not had opportunity to memorialize their wishes in an advance directive, or had the requisite capacity to understand and sign such a legal

document, there are ways that their families can continue to help with medical decisions. As summarized by the ABA Commission on Law and Aging, when an individual cannot make health care decisions and has not designated a surrogate to make decisions on his or her behalf, ". . . in 38 states the statute prescribes that the highest person available and willing to make health care decisions becomes the surrogate."[317] These statutes typically list natural relatives in order of priority, such as spouse, adult children, parents, siblings, ". . . and so on through the family tree."[318] When these statutes come into play, it is usually not following a judicial determination that the patient lacks capacity. Rather, it is based on the determination of the attending physician, sometimes in consultation with another physician in order to ensure that the individual is not unnecessarily being deprived of the right to make these important decisions on their own.

Florida seems to be unique in that it specifically notes that when a patient is "incapacitated *or [has a developmental disability]* . . ." his or her physician can look to next of kin to make health care decisions for the patient [emphasis added].[319] While this law seems to have been passed at the urging of parents of adults with developmental disabilities in order to facilitate their ongoing involvement in the individual's health care, it remains problematic because it presumes the incapacity of adults with developmental disabilities—disabilities which may or may not involve any cognitive impairment whatsoever—who may be perfectly capable of making their own health care decisions.

Although these statutes may alleviate the need for guardianship, they are often not taken into consideration when alternatives to guardianship are being considered. It is vital that they be understood and considered in order for guardianship to remain the last resort. Additionally, doctors and other medical professionals need to be trained to work with patients with disabilities—including intellectual disabilities, cognitive impairments, and psychiatric disabilities—and their families as appropriate to maximize the patients' ability to make their own medical decisions. There is a strong argument to be made that the ADA requires providers to accommodate people with disabilities in the decision making phase of medical treatment in the same way they are required to provide an accessible exam table, American Sign Language interpreters, or allowing a patient to bring a service animal to an appointment.

Educational Decisions

As discussed earlier, when an individual reaches the age of majority (generally 18 years of age), they are entitled to make decisions for themselves, and their parents no longer have any legal right to make decisions on their behalf or obtain confidential information unless the adult child has given permission. However, this does not mean that parents who are told by school staff that they need to seek guardianship as soon as their son or daughter with disabilities turns 18 are getting sound advice. There are several alternatives that enable parents to continue to stay involved in the education of their son or daughter after they've turned 18.

Powers of Attorney

As discussed in Chapter 6, many parents of youth with developmental disabilities are advised by school personnel that they need to obtain

guardianship when their son or daughter turns 18 or face being denied a say in their adult child's education. This advice often raises concerns for parents of students who remain eligible for IDEA services through age 21. However, according to guidance from the Office of Special Education Services (OSERS):

> . . . if State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that student can become the educational rights holder who invites family members to participate in the IEP meeting. If the adult student does not want to have that role, he or she can execute a power of attorney authorizing a family member to be the educational decision-maker.[320] The OSERS guidance goes on to suggest that supported-decision making—discussed further in the next section—is likely to be a good option in these situations as well.

". . . if State law permits parental rights under the IDEA to transfer to a student who has reached the age of majority, that student can become the educational rights holder who invites family members to participate in the IEP meeting."

Educational Representatives

In addition to the option of a power of attorney, in some states, there is a procedure for the involuntary appointment of an educational representative for an adult student who, through a process recognized in state law, is deemed unable to make educational decisions but who has not been adjudicated incapacitated. For example, in Connecticut, an educational representative can be appointed for an adult student when two professionals (e.g., physicians, psychologists, nurse practitioners) have certified in writing that the individual cannot make educational decisions.[321] While this process may make it less likely that a parent will seek guardianship in order to continue to play a role in their adult son or daughter's education, it still acts as a revocation of an adult's rights to make decisions for his or herself and with virtually no due process, which is highly problematic.

International Best Practices

Many interpret the CRPD to categorically reject guardianship. Article 12 requires Parties to the convention to "recognize that [people] with disabilities enjoy legal capacity on an equal basis to others in all aspects of life" and to "take appropriate measure to provide access by a person with disabilities to the support they require in exercising their legal capacity."[322] Countries that have signed the treaty have responded to this mandate in a variety of ways, and in many cases it is not clear how successful these evolving legal frameworks have been or whether they will have the staying power to permanently supplant guardianship. However, because the CRPD requires states to file reports describing how they are meeting their obligations, including the requirements of Article 12, advocates and policymakers in the United States will be able to track the evolution of these initiatives over time.[323] Since the federalist system in America

that gives individual states the responsibility for developing and maintaining their own guardianship system is relatively unique in the world, there may be some innovations that other countries adopt that may prove more difficult for the United States to implement on a nationwide basis. However, it remains useful to examine the efforts of countries that have responded to the Article 12 mandate with effective reforms across decision making areas.

The Trend Toward the Alternative of Supported Decision Making

Supported decision making (SDM) is an emerging, less-restrictive alternative to guardianship that is currently used both within the United States and abroad. Scholars have recognized it as having the strong potential for resulting in favorable outcomes in the lives of people with disabilities,[324] and studies are underway to further verify such outcomes.

Definition of Supported Decision Making

Supported decision making (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, allowing them to make their own decisions without the need for a substitute decision maker, such as a guardian.

Definition of Supported Decision Making

Many view the CRPD as the impetus for current reform efforts to advance SDM. Article 12 of the CRPD requires signatory nations to both recognize and assist in helping people with disabilities exercise legal capacity on an equal basis to others.[325] Used by the CRPD Committee, the term *supported decision making* describes one of the ways a person can be assisted in exercising legal capacity.[326]

There is no singular definition or model of SDM.[327] However, it 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, allowing them to make their own decisions without the need for a substitute decision maker, such as a guardian.[328] SDM works in the same way that most adults make daily decisions—by seeking advice, input, and information from others who are knowledgeable and whom the adult trusts. As one interview participant explained:

> *"[N]o one is ever truly independent. We're interdependent on one another and that's true for people with all kinds of disabilities and people without disabilities."*

> no one is ever truly independent. We're interdependent on one another and that's true for people with all kinds of disabilities and people without disabilities.

All forms of SDM operate on three core elements:

- A person's autonomy, presumption of capacity, and right to make decisions on an equal basis with others

- A person's involvement in a decision making process that does not remove his or her decision making rights
- The recognition that people will often need assistance in decision making through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language[329]

Benefits of Supported Decision Making

SDM has the potential to provide people with disabilities the support needed to understand their options while ensuring that they still retain ultimate legal decision making authority, unlike guardianship.[330] In discussing potential outcomes of that approach, many point to studies that have found the following:

- People with intellectual and developmental disabilities who exercise greater self-determination—who are "causal agents" with more control over their lives[331]—have better life outcomes and quality of life,[332] including being more independent, more integrated into their communities, better problem-solvers, better employed, healthier, and better able to recognize and resist abuse. People with intellectual and developmental disabilities learn through the process of making decisions, and self-determination, if taught, can also be learned.[333] As one interviewee explained, "It's not about protecting someone. It's about teaching them how to best protect themselves."

People with intellectual and developmental disabilities who exercise greater self-determination . . . have better life outcomes and quality of life . . .

- Older adults with more self-determination have improved psychological health, including better adjustment to increased care needs.[334] Older adults with progressive dementia are more likely to retain cognitive function when they use their cognitive skills.[335]
- Self-determination has been linked to better life outcomes for youth with disabilities in foster care.[336] Additionally, outcomes for other students with disabilities are better when they are empowered to exercise self-determination.[337] Those with self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes.
- In absence of an approach like SDM, when denied self-determination, people can "feel helpless, hopeless, and self-critical,"[338] and experience "low self-esteem, passivity, and feelings of inadequacy and incompetency" and a "decrease in their ability to function."[339]
- Although not generalizable given limited number and size, professionally evaluated pilot programs have found that SDM led to positive outcomes for participants, including greater community inclusion, improved decision making skills, increased social and support networks, and increased self-confidence, happiness, and willingness to try new experiences.[340]

Some of those interviewed for this project put the reason for using SDM into human terms. Said one interviewee, "He's a human being. He has likes and dislikes; we all do. And why do we not respect that?" Another focused on the adage that "to err is human" when the interviewee said, "We have to acknowledge that everyone, whether they have a cognitive disability [or not], make[s] bad decision[s] so we frequently have to acknowledge and respect the right for [a] person to make a 'wrong' decision."

Areas for Greater Study with SDM Models

While many studies extol the benefits of SDM models, as is the case with any alternative, there still exists the potential for unintended consequences or experiential disparities based on type of disability, which warrant further study:

- **Substituted Decisions:** Supporters in a SDM model may misunderstand their role and substitute their decisions for the person with a disability, or unintentionally lead the person to a predetermined outcome "through issue-framing, inaccurate assessment of [the person's] preferences, or simple conversations" in which the person gives deference to supporters.[345] One must ensure people with disabilities are not, in fact, disempowered through undue influence by so-called supporters.[346] Some interviewees expressed concern about the potential for abuse under a supported decision making model: "[C]ertainly using support decision-making would offer a real opportunity . . . if one or more people were inclined to take advantage or exploit an individual. And it's unclear to me what the

Supported Decision Making Furthers the Goals of U.S. Federal Policy

SDM furthers the goals of U.S. federal policy, including those under:

- The Americans with Disabilities Act, which secures the basic civil rights of people with disabilities, including the right to self-determination, community integration, and the right to receive accommodations in order to participate in a governmental programs and employment and access the services of businesses that are generally open to the public, such as doctor's offices and banks.[341]
- The Individuals with Disabilities Education Act, which mandates transition planning that should empower young adults with disabilities to make choices as they enter adulthood.[342]
- The Rehabilitation Act because individuals who are active participants in an individualized plan for employment and decisions regarding their employment generally are more likely to achieve positive employment outcomes.[343]
- Medicaid and Home and Community Based Services, which are developed with an emphasis on person-centered planning.[344]

ramifications would be beyond just general criminal laws."

- **Court Oversight:** If an adopted SDM model requires agency or court oversight, it might have the effect of operating very similarly to guardianship (e.g., people could be subjected to continuous monitoring).[347]
- **Unwanted Assistance:** SDM may conflict with a person's right to make his or her own decisions without support, should the model be promoted or enforced even when an adult does not want that kind of assistance at all.[348]
- **Disability-Specific Emphasis:** So far, SDM has gained more headway as an alternative to guardianship for people with intellectual and developmental disabilities, and most SDM pilot projects in the United States have targeted people with intellectual disabilities. However, SDM has not yet been embraced to the same degree as a viable option for older adults with cognitive impairments[349] or people with psychiatric disabilities.[350]
- **Application for Those with Severe Disabilities:** Likewise, further exploration is warranted regarding how SDM could work for people with severe intellectual and other disabilities.[351] As one interviewee said of her brother, "He does not use words in any form, so he does not type, he does not speak in words, he does not sign his name as a signature, and he does not use an alternative communication device. From a legal perspective, it would be very difficult for him to create alternative detailed support plans." However, one interviewee with a different significant disability explained how SDM worked for her, using the voting context as an example: "My Mama [and I] have a system where I slap her left hand or right hand to make my choice. If I don't slap either one, it means I don't like either choice. So anyway, I voted three times now for president and governor."

Under SDM, it is the person with a disability who is the decision maker. The supporter(s) solely explain(s) the issues, and may interpret the signs and preferences of the person to others based on their prior knowledge of and relationship to the individual.

How Supported Decision Making Works

When it comes to SDM, one size does not fit all. As the CRPD Committee clarified, "Supported decision-making can take many forms."[352] Supporters may help the person understand the choices at hand, communicate that person's decisions to others, or even "help others realize that a person with significant disabilities is also a person with a history, interests and aims in life, and is someone capable of exercising his/her legal capacity."[353] As the U.S. Health and Human Services' Administration on Community Living stated regarding SDM:

> solutions . . . are different for each person. Some people need one-to-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. With supported decision-making the possibilities are endless.[354]

Under SDM, it is the person with a disability who is the decision maker. The supporter(s) solely explain(s) the issues, and may interpret the signs and preferences of the person to others based on their prior knowledge of and relationship to the individual. "Even when [a person] with a disability requires total support, the support person(s) should enable the individual to exercise his/her legal capacity to the greatest extent possible, according to [his or her] wishes."[355]

SDM arrangements need not be documented in a formal written agreement, although some are in order to encourage third parties to rely on the decision that is made.[356] The capacity to enter into an SDM agreement has been contrasted with the capacity to contract; an SDM agreement is seen not as a contract, but rather as a way in which an adult with a disability authorizes (an) other person(s) to advise and consult in that adult's decision making.[357]

In its purist form, SDM is an *alternative* to guardianship. However, the National Guardianship Association has recognized the best practice of using SDM principles *within* guardianship as well, stating that if guardianship is "necessary," "the supported decision-making process should be incorporated as a part of the guardianship."[358] Some guardians interviewed as part of this project linked guardianship with promoting SDM or restoration of legal decision making rights:

> Guardianship to me is being able to explain the situation and help the person make the decision but helping them make the most educated decision and just being there if they need somebody.
>
> Our job as guardian was to keep him safe, and to help him grow to where he could make decisions on his own with support.

Past reforms represented "tinkering with the existing guardianship system" to provide guardians with education and training on implementing person-centered decision making, enhance monitoring and accountability to ensure that goal, and assuring care and life planning for older persons and people with disabilities.[359] However, as has been previously noted, the U.N. Committee on the Rights of Person with Disabilities represents more of a departure, taking the position that any form of guardianship is inconsistent with Article 12 of the CRPD and with the spirit of SDM.[360] It remains to be seen whether SDM can coexist within guardianship or whether guardianship is anathema to SDM, but as one scholar has noted, "guardianship is here to stay, at least for now."[361] Given that fact, guardianship reform efforts, such as those by the National Conference of Commissioners on Uniform State Laws that recognize the role guardians and courts should have in "encourag[ing] the development of [a person's] maximum self-determination and independence"[362] are still worthy of promotion.

International and U.S. Support and Advancement of SDM

Internationally, SDM has gained visible momentum in academia, case law, regional courts and bodies, legislative reform, the creation of centers and institutes, nonpeer reviewed publications, conferences and symposia, and United Nations (UN) activity. At least

162 countries have ratified the CRPD, driving widespread change.[363] Among others, the governments of Canada, Great Britain, Ireland, parts of Australia, parts of New Zealand, parts of Germany, Bulgaria, Israel, the Czech Republic, Norway, Sweden, and India have either adopted or are exploring the adoption of SDM.[364] Here are a few international examples of how SDM has been adopted:

- Some Canadian providers are using a formal SDM model where a person with a disability may enter into a private legal agreement with one or more people who will provide assistance with decision making or act as formal decision making representatives for the person, with continuing and active involvement by the person.[365]
- In Sweden and some other European nations, a legal mentor or personal ombudsman can be judicially appointed to act as a decision making assistant for a person who is found incapable of making any or all their decisions alone.[366]
- In a South Australian SDM project, a person would nominate one or more people to act as a supporter and memorialize that arrangement in a non-statutory SDM agreement. An extra person (called a *monitor*) helped with the process and identified problems if they occurred.[367]

The move from substitute decision making (traditional guardianship) to SDM is a paradigm shift in how society thinks about the decision making abilities of people with disabilities,[368] and the United States has lagged behind the international community in moving that direction.[369] Not only has the United States not ratified the CRPD, but domestic guardianship reform efforts frequently "accept the predominance of a legal regime that locates decision-making in the surrogate or guardian, and not in the individual being assisted."[370] In contrast to guardianship, SDM "retains the individual [with a disability] as the primary decision maker, while recognizing [he or she] may need assistance—and perhaps a great deal of it—in making and communicating a decision."[371]

The move from substitute decision making (traditional guardianship) to SDM is a paradigm shift in how society thinks about the decision making abilities of people with disabilities, and the United States has lagged behind the international community in moving that direction.

However, as it has become increasingly clear through decades of guardianship reforms that the guardianship system has intractable problems; SDM is beginning to get a foothold in the in the United States through advocacy and discourse of constituents to legislatures and policymakers, and through the courts. For example, since 2012, court decisions favoring SDM over permanent guardianship have come out of New York, Virginia, Massachusetts, the District of Columbia, Florida, and Vermont, among others.[372] State legislatures are beginning to formally recognize SDM as well,[373] such as by enacting statutes formally recognizing SDM Agreement Forms (Texas[374] and Delaware[375]), identifying SDM as an option in special education (District of Columbia[376]) for adult students and in areas of medical decision making (Maryland[377]), and ordering SDM-related studies (Virginia[378],

Maine[379], and Indiana[380]). There also exists keen interest in specifically codifying SDM as an alternative to guardianship within state laws, considering, as of August 2017, there were at least half a dozen states with pending SDM-related bills in their legislatures.[381] Moreover, SDM pilot projects have emerged in states including Massachusetts[382], Maine, North Carolina[383], South Carolina, New York,[384] and Texas,[385] among others. Vermont, for example, has convened a statewide task force of agencies working with older adults and people with disabilities designed to incorporate SDM theory and practice into its service systems.[386]

The value of promoting SDM is being recognized in federal policy, as well. In 2014, the Administration for Community Living (ACL) within the U.S. Department of Health and Human Services began funding the National Resource Center for Supported Decision-Making to conduct cutting-edge research, create educational programming, and gather and develop multidisciplinary best practices and tools to further establish SDM as a recognized and viable decision making support for people with disabilities and older adults across the United States.[387] SDM has been promoted by the American Bar Association Commission on Law and Aging[388] and the National Guardianship Association,[389] as well as a number of federal advisory bodies[390] and federal agencies, including, for example, the Department of Education.[391] SDM has also been the topic of national stakeholder summits, including those convened by the American Bar Association,[392] Quality Trust for Individuals with Disabilities, the Burton Blatt Institute, the Council on Quality and Leadership,[393] the Autistic Self Advocacy Network (ASAN), and the National Resource Center for Supported Decision-Making.[394]

The American Bar Association has also formally recognized the importance of advancing SDM. In August 2017, its House of Delegates approved a resolution urging the amendment of guardianship statutes to require that SDM "be identified and fully considered as a less restrictive alternative before guardianship is imposed" and be considered a "grounds for termination of a guardianship and restoration of rights."[395]

This model law, known as the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act (UGCOPAA), formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship.

Perhaps most exciting from an SDM reform perspective is the completion of the revisions to the UGPPA. The UGPPA was originally approved by the Uniform Law Commission in 1982, amended in 1989, and last revised in 1997. Nearly 20 states have enacted some version of the Act. A drafting committee began the process of revising the UGPPA in early 2015 and, on July 18, 2017, the Uniform Law Commission approved the resulting revisions. This model law, known as the UGCOPAA, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship. The UGCOPAA no longer uses the term *incapacity* and requires that, in order to appoint a guardian, the court must find by clear and convincing evidence that the individual "is unable to receive and evaluate

information or make or communicate decisions, even with appropriate supportive technological assistance, or supported decision-making."[396] The model law has been approved by the ABA House of Delegates and is ready for adoption by state legislatures. Given the influence that the UGPPA has had on the guardianship laws of many states and the interest in guardianship reform that seems to be developing across the country, the UGCOPAA is likely to have a strong impact on state law in the coming years.

Next Steps for Supported Decision Making as an Alternative to Guardianship

One of the greatest barriers to full adoption of SDM is the lack of reliable data specifically tying it—and not only the concept of self-determination, which has been highly studied—to improved life outcomes.[397] To better guide SDM models,[398] validated empirical evidence is needed regarding best practices in SDM, including effective and support structures and methods, and whether people who engage in SDM are more self-determined, autonomous, experience better life satisfaction, and achieve meaningful community living and participation.[399] There is also little evidence on how SDM is applied in jurisdictions in which it is used due to a lack of data collection regarding the number of SDM arrangements; of demographic data of those who use SDM and who act as a supporters;[400] and how SDM can work for people with severe intellectual disabilities and other populations, among other areas.[401] To help fill this research gap, the National Resource Center on Supported Decision-Making is currently conducting qualitative and quantitative studies to document the nature, use, barriers, and outcomes of SDM by older adults and people with intellectual and developmental disabilities,[402] the results of which are pending.

Scholars have recommended some other promising SDM-related safeguards and proposed reforms, including:

- Providing sufficient resources for widespread education on SDM to the general public, people with disabilities, third parties working with people with disabilities and supporters, and the legal and judiciary systems. There should be standards of conduct for supporters,[403] and those supporters should have access to training on what it means to support someone with decision making and how to minimize unintended undue influence. Training must help supporters understand "the total lack of any decisional power" being a supporter conveys.[404] Family members and other supporters must receive practical information to understand the fundamental philosophy behind SDM, how to use strategies of communication and conflict resolution, how to manage power differentials and the risk of undue influence, how to balance enabling rights and managing risk, and how to collaborate with other supporters.[405] Just having an SDM regime established in law is not enough.[406]
- Funding more geographically and demographically diverse projects and pilots that specifically test SDM models, and use SDM and the court systems to restore people's rights as a matter of law,[407] particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.

- Requiring states to ensure that self-advocacy skills are included in school curricula and to support and promote self-advocacy organizations.[408] For SDM to firmly take root, it must be promoted in childhood, including within educational programming and school-to-adult transition planning.
- Placing limitations, when formal SDM agreements are used, on how or if supporters can act with regard to certain kinds of important decisions, creating legal prohibitions that would disallow supporters from acting in transactions in which they have a conflict, and ensuring the involvement of more than one supporter.[409] Using examples the New York pilot intends to apply, these safeguards could include the use of monitors, who are chosen by the person with a disability for all or some decisions, or "mentors," who can serve as the person's "constant and trusted advisor [and] a relationship with [him or her] that coincides with the progressive decline of neurodegenerative conditions."[410]
- Establishing a state or official office that has the power to investigate allegations that a supporter acted improperly and to resolve conflicts that might arise without automatically turning to more restrictive forms of intervention, like guardianship.[411]
- Funding the creation of programs that directly provide supports for people who have no one suitable to act as a supporter,[412] and writing laws and policies that facilitate access to formal and informal supports for large number of people requiring assistance with day-to-day issues.[413]

While there are numerous areas requiring future study, SDM has demonstrated promise as a comprehensive alternative to guardianship that avoids many of the widely recognized problems with guardianship's impact on people's lives.[414]

In order to achieve the promise of the ADA, we must continue to improve opportunities for people with disabilities to exercise self-determination, make choices, and take risks. While there may be steps that can be taken to improve these opportunities within guardianship, in the estimation of the Council after an extensive and thorough examination of the complex issues involved, the greatest promise lies in recognizing the legal capacity of people with disabilities on an equal basis with others in all aspects of life and in taking steps to provide access by people with disabilities to the support they may require in exercising their legal capacity.[415]

Chapter 9: Stakeholder Experiences with the Guardianship System

Overview of NCD's Qualitative Study

For this report, NCD funded an in-depth qualitative study on the use and nature of guardianship. NCD's research team worked in partnership with researchers at the Institute on Disabilities at Temple University (the Institute on Disabilities) to interview stakeholders around the country and analyze trends. The stakeholders interview included people with disabilities subject to guardianship, people with disabilities using alternatives to guardianship, family member guardians and/or supporters, and representatives chosen for their expertise in advocacy, law, court operations, and the professional services for people with disabilities. NCD's research team conducted 46 interviews that captured a wide range of life experiences and perspectives on guardianship and alternatives to inform this report. This chapter reports the analysis of those interviews, highlights salient themes, and shares some of the stories and experiences shared in the participants' own words. The full analysis can be found on NCD's website.

Methodology

From February 2017 through April 2017, the NCD research team, in partnership with the Institute on Disabilities, conducted and analyzed a total of 46 qualitative interviews. The participants were identified through extensive outreach to the members of the advisory boards established for this NCD project; the National Resource Center for Supported Decision-Making; public and private guardians; and national and local disability, self-advocacy, and aging networks. Researchers used a snowball sampling process, in which existing participants recruited future participants from among their acquaintances. The research team used of this style of sampling rather than a probability sampling process in order to reach individuals who would have otherwise been difficult to involve. Selection of participants also factored in their geographical diversity, individual characteristics, level of need for support, and individual experience.

Research Sample

The original goal was to interview a balanced sample of 10 participants from each of the four categories. However, despite widespread outreach, there were challenges in locating people subject to guardianship who were able to be interviewed. Reasons for this likely are related to complications associated with getting the approval from the guardians involved,[416] constraints related to conducting interviews outside the District of Columbia remotely by telephone or video conference, and, in some cases, the reported severity of disability experienced.

As a result, the final tally of participants included:

a. 6 people with disabilities subject to guardianship, one of which identified as being under "partial" guardianship and another that identified as having a plenary guardianship subsequently changed to a limited one;
b. 12 people with disabilities using alternatives to guardianship, including at least 3 who had previously been subject to guardianship but had subsequently had their rights restored;
c. 16 family member guardians and/or supporters; and
d. 12 representatives chosen for their expertise in advocacy, law, court operations, and professional services for people with disabilities.[417]

The participants included residents of California, Delaware, the District of Columbia, Florida, Georgia, Illinois, Kentucky, Kansas, Massachusetts, Minnesota, New York, North Carolina, Pennsylvania, Texas, Utah, Virginia, Washington, and Wisconsin. Participants included people and/or family members of people with ID/DD, acquired and/or traumatic brain injury, psychosocial disabilities, sensory and physical disabilities, and dementia. Some participants reported the presence of co-occurring disabilities. Given that the goal of 40 interviews was exceeded and there is obvious diversity of category and within each category, the interviews provide excellent data to analyze.

Interview Questions

The interview protocol that the NCD research team developed included input from the project's advisory committee members. The research team developed four sets of interview questions, one for each of the four participant categories. The interview questions address the project's previously identified research questions, which provided a general framework for the issues to be explored. The research questions NCD sought to answer were as follows:

1. Are people with disabilities receiving fair treatment within the legal system with respect to guardianship?
2. Is supported decision making a viable alternative to guardianship? If so, does it lead to better outcomes or are there some negative unintended consequences to using this alternative?
3. Are people with disabilities who may need decision making assistance and their families being provided with sufficient information about the guardianship process and possible alternatives to make informed and appropriate decisions?
4. How does guardianship impact people with disabilities and their families? Does guardianship help improve outcomes of health, safety, and protection for people?
5. How does the current use of guardianship align or conflict with other U.S. national disability policy goals and initiatives, including the goals of the ADA and its community integration mandate and principles of due process under the law?

Interview Method

The interviews were semistructured in nature to allow the interviewer and participant to engage in a formal interview while simultaneously

encouraging the exploration of unique issues and topics that emerged during the interview. The interviewers were trained to tailor their questions to the specific respondent and/or interview context and situation. The goal was to solicit the broadest array of information, opinions, and ideas. The protocol was designed to keep the interview length to no more than one hour, although some actual interviews exceeded that time frame or were broken into multiple interview sessions at the participant's preference. The protocol emphasized the voluntariness of the interview and the openness of the dialogue—that is, that there were no right or wrong answers, that the participant did not have to answer any questions he or she did not want to answer, and that the participant could take a break from or end the interview at any time.

Due to the geographical diversity of the participants, most of the interviews were conducted by telephone or videoconferencing, while others were conducted in person. Two participants asked to submit their responses in writing as an accommodation. The interviewers were all law students at the American University School of Law's Disability Rights Law Clinic,[418] under the supervision of NCD's research team. They were trained on how to use the interview protocol, conduct a qualitative interview, and accommodate people with disabilities. A third-party contractor recorded and transcribed the interviews and then the NCD research team redacted personally-identifiable information to protect the privacy of the participants. The research team next analyzed the electronic transcripts of each interview, the notes that the interviewer took during the course of the interview, and email communications about aspects of the interviews from interviewers to the project coordinator.

Analysis and Salient Themes

After reviewing and analyzing the interviews and other documents, NCD researchers were able to point out themes that emerged from the data from each of the four categories of participants and organized those themes based on the research questions posed by NCD. The Institute on Disabilities also analyzed the interview results within each participant category, grouping separately the interviews of people with disabilities subject to guardianship, people with disabilities who used alternatives to guardianship, family member guardians and supporters, and professional representatives.

Treatment Within the Legal System

Across participant category, NCD's research identified three salient overarching themes regarding the treatment of people with disabilities within the legal system of guardianship. These themes were that:

- Judges do not fully appreciate what guardianship is, how it limits people, and what other alternatives are available.
- There are differences between legal rights and how people experience the legal system, actors, and spaces in practice.
- People with disabilities are not adequately assessed in terms of their ability to make decisions and function.

The results of the data analysis for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD's research found that people with disabilities subject to guardianship expressed positive, negative, and neutral reactions about their treatment within the legal system with respect to guardianship.

There were people who described positive experiences with their lawyers, in court and/or with their guardians. For example:

- One person in her early 40s described being under a "partial" guardianship since she turned 18 and identified as having a developmental disability. Her parent served as her primary guardian, with other family members serving as successor guardians, if needed. She said: "[Guardianship] was my choice. [I wanted] somebody available to help with things, and [I] am glad I do. I don't think I would change it."

Other people subject to guardianship had negative experiences, which included being prohibited from accessing money and changing guardians, inattentive lawyers, and lack of an explanation of rights. For example:

- One person, who was a veteran and reportedly had psychosocial disabilities and a history of substance abuse, reported: "I had a lawyer. Someone got him [for me.] . . . He made me sign the papers. If I had known what this was about, I would never have signed the papers. He never checked up on . . . me. He just dumped me . . . I don't need no damn guardian." This participant indicated that his lawyer did not represent him in the way he wanted, that he did not get adequate opportunity to talk to his lawyer before the guardianship hearing, and that he did not know if the lawyer told the judge what he wanted because he did not go to court. However, this participant was aware that he could go back to court to ask that his guardianship be removed, and he said he planned to do that.

"I had a lawyer. Someone got him [for me.] . . . He made me sign the papers. If I had known what this was about, I would never have signed the papers. He never checked up on . . . me. He just dumped me . . . I don't need no damn guardian."

People with disabilities using alternatives to guardianship

NCD research found that people with disabilities using alternatives to guardianship, including those who had had their guardians removed and their full rights restored, had no positive responses to the treatment of people with disabilities within the legal system with respect to guardianship.

In terms of negative responses, participants reported that society took for granted that every person with disabilities requires guardianship. For example:

- One person with a significant developmental disability stated: "At my IEP meetings during high school, the school told my parents they needed to get a guardianship of me, so that they could still make decisions for me . . .

Just because I do not talk doesn't mean I'm incompetent."

Additionally, some interviewees felt that the legal system, courts, lawyers, and evaluators did not spend enough time to adequately assess an individual's level of function. For example:

- One woman with a psychosocial disorder who had been under state guardianship at one point in her life reported: "I did [have an attorney] but I only spoke to him for about 10 minutes, about an hour before we went to court. . . . He just read over my reports and said, 'Oh, it doesn't look good.'"

These interviewees also noted the lack of education they received on their civil and legal rights and defined *guardianship* as the taking away of a person's rights.

"At my IEP meetings during high school, the school told my parents they needed to get a guardianship of me, so that they could still make decisions for me . . . Just because I do not talk doesn't mean I'm incompetent."

Family member guardians and/or supporters

NCD's research found that family member guardians and supporters expressed positive, negative, and neutral reactions regarding how people with disabilities are treated within the legal system with respect to guardianship.

Multiple participants described the court experience as positive, stating they felt the person with disabilities was respected—although sometimes absent—and that the person's rights, including right to seek revocation of the guardianship, were reviewed. For example:

- One family guardian reported that her son was treated "very politely" in the court process. She went on to say: "He had his own representation. He did have a lawyer. They only met right before. My lawyer shared all that information with this other attorney, and they met privately before coming in, so I wasn't there. I couldn't answer questions for him or deter questions or anything like that. . . . And . . . our guardianship judge, . . . he's been great. . . . he's not pro-guardianship, he's pro-family . . . he's not someone that I can't approach."
- Another family guardian reported: "[T]he judge that did our proceedings, I thought did a marvelous job. . . . [H]e was very good in explaining to us what this meant, that it's serious—taking people's rights away—and I thought he was very good."

Many interviewees indicated that the people with disabilities did not, in fact, understand the legal proceedings, that their rights and the nature of the legal process were not adequately explained to them, and that their legal counsel had limited communication with them. For example:

- One guardian said: "[T]he judge had said to [my daughter], 'Do you want guardianship or do you not?' . . . [and] she said, 'Sure, yes, I'll have guardianship.' But I don't think [she] really understood what was happening in the court system at that particular time."
- Another guardian said: "We never had a hearing and never went to court. Because

of [my daughter's] disability, people totally ignored that . . . But she had someone represent her who was appointed by the state who came in and spent 10 minutes talking to us. [Because my daughter does not communicate verbally], the lawyer did not [know] how to communicate with her [and] then signed off on the guardianship, and we never went to court."

- One former guardian of her son, who had his rights eventually restored, reported: "[T]he lawyer that the court appointed . . . came for 2 hours, never went to his job site, never went to where he volunteered to actually see him moving about and being functional." She went on to say that the court focused on her son's diagnosis and did not "take the time to actually study who's [in front of them] and their functionality."

"[T]he lawyer that the court appointed . . . came for 2 hours, never went to his job site, never went to where he volunteered to actually see him moving about and being functional." She went on to say that the court focused on her son's diagnosis . . .

Some interviewees who were family members and/or supporters described the person subject to guardianship as being seen as not a full person and not existing in the eyes of the law. Some defined *guardianship* as the "closest thing to the death sentence" and "like being in prison."

Professionals

NCD's research found that the professionals interviewed had positive, negative, and neutral reactions regarding how people with disabilities are treated within the legal system with respect to guardianship.

There were professionals that saw the legal system as designed to protect the rights, including legal representation and due process, of people with disabilities, but noted that research is needed to better understand how that system actually works in practice and how people with disabilities experience it. For example:

- One senior law attorney with decades of experience in guardianship policy concluded: "[W]e got the laws in pretty good shape. The concern is a less than vigorous recognition of those due process rights in some courts."
- Another retired judge agreed: "[M]uch of the procedural protections that are provided in the [guardianship] statute are ignored."

Another retired judge agreed: "[M]uch of the procedural protections that are provided in the [guardianship] statute are ignored."

A few professionals noted the need to promote, where necessary, limited rather than full guardianships and/or conservatorships. For example:

- One professional stated: "I think that guardianship is much more palatable as

something that we have in a country that believes in individual freedom and liberty when it's limited to actual needs as opposed to when it's general and premised on the notion that people are globally incompetent." He went on to say that it was important to look at rights not as a "bundle of sticks . . . that you either give or take away. [It's about] looking at those sticks individually in determining only which decision-making capacity [that] individual lacks and taking only those [rights] away."

Some professionals remarked that, within the legal system, people with disabilities are treated not as individuals, but as stigmatized stereotypes; receive variable due process, without adequate legal representation; and are not adequately assessed in terms of their capability to make decisions and function. For example:

- One professional concluded: "[P]eople [in guardianship proceedings] who are entitled to representation get somewhere between okay and crap . . . Pro bono programs are primarily for parents and practitioners in getting the cases into court and not for representing the people with disabilities . . . There's no provision for counsel in [my state's] statute [for people with developmental disabilities].
- One professor, who also had experience being a guardian for his adult child stated: "I worry about whether the hearings are rubber-stamped formal or whether they are genuine interrogations [and] inquiries . . . "

Some interviewees who are professionals also reported that judges and lawyers have inadequate training, understanding, and experience with the needs of people with disabilities. For example:

- One developmental disability service provider stated: "I understand there's very little teaching in law schools around disabilities and so they don't really get disabilities and they don't get guardianships and what it may mean for the person with the disability."
- One law professor further explained: "[T]he way the [guardianship] laws were established [are] based on kind of a presumption of incompetency depending on the person's label of disability . . . I don't think the legal system treats people well. In the guardianship process, I think judges may want to do the right thing, but they don't know enough about the [disability] themselves to understand that, even if someone has a label of intellectual disability . . . or can't even speak . . . [they] still may be able to make decisions for themselves so long as they can get the support that they need."
- For one professional interviewed, it came down to values: Judges may be "less likely to care about the due process issues and less likely . . . to value the individuals in front of them" because of a priority on expediency and judicial economy.

"[P]eople [in guardianship proceedings] who are entitled to representation get somewhere between okay and crap . . .

Not all professionals agreed:

- One attorney at a public guardian agency stated that she has "seen some good judges say, 'Wait a minute . . . do you ever want to drive, do you want to vote, do you want to do these things? . . . Are you okay with your mom making your decisions?'"

Additionally, in terms of guardianship, there were professionals who argued that the expectation should always be the least restrictive intervention in terms of decision making support; and a presumption of competence. Professionals also noted that education about rights should be personalized and not limited to the courtroom. For example:

- "There needs to be a special attention given to and the way that people learn information and especially in the setting that or the circumstance that needs to be individualized to some degree or as much as possible to accommodate the various ways in people and people with disabilities can understand that kind of information."
- "[I] don't think being in a stressful courtroom should be the first time that that discussion is being had, I think [it] . . . can be very intimidating for people."

One attorney at a public guardian agency stated that she has "seen some good judges say, 'Wait a minute . . . do you ever want to drive, do you want to vote, do you want to do these things? . . . Are you okay with your mom making your decisions?'"

Supported Decision Making

NCD's research identified two salient overarching themes among the interviews when it came to supported decision making:

- No support system, including guardianship and supported decision making, is free from risk of exploitation or abuse.
- For people with significant support needs, supported decision making might not be as easy to implement well.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD research found that people with disabilities subject to guardianship expressed positive and neutral reactions regarding supported decision making as a viable alternative to guardianship.

Participants responded positively to the definition of supported decision making, although many were not previously familiar with the term. Some described a relationship with their guardian as akin to the supported decision making model. For example:

- "If I don't understand something all I have got to do is tell [my guardian] and she will help me understand it."

People with disabilities using alternatives to guardianship

NCD research found that people with disabilities using alternatives to guardianship expressed positive reactions regarding supported decision making as a viable alternative to guardianship.

Participants recognized that all people rely on natural supports to understand and make decisions and sometimes make poor decisions and that, in that sense, people with disabilities should be seen as no different than people without disabilities. For example:

- One person said: "I think there are people with and without disabilities who make really bad decisions and would benefit from someone helping them learn how to live healthier and safer lives. To me, supported decision-making is what really good family and friends do. It's having conversations with each other about needs and wants and coming to a decision with their help when needed. My mama still gets helps from my grandpa and grandma when she has a big decision to make. Buying a car, having surgery, taking a new job. We all need each other [and should] respect our rights to make the final decision."
- Another person said: "I believe that people should be able to make their own decisions, but they also have to deal with the consequences of the decisions they make. If someone is there telling another person what they should do, . . . they're not going to be able to make their own judgments about situations and figure out their own problem-solving for certain situations."

Family member guardians and/or supporters

NCD research found that family members and/or supporters expressed positive, negative, and neutral reactions regarding supported decision making as a viable alternative to guardianship.

There were family members who described supported decision making as a form of self-determination. They reported that most people can and should have the right to make their own decisions and that people with disabilities should be involved in the decision making process. For example:

- A mother who uses supported decision making with her son said: "He's a human being. He has likes and dislikes; we all do. And why do we not respect that?"
- Another participant who supports her adult cousin with multiple sclerosis emphasized his right to make his own decisions: "[H]e had a hospitalization . . . in which . . . the hospital staff were recommending that he move from [the] hospital to . . . a residential rehab facility. And he didn't want to go. He said, 'I want to go home.' . . . I really don't think it's a good decision, but it's his decision and he's decided he wants to go home, so I will make sure that he has all the support in place."
- A guardian said: "I don't make any decisions for my son without him—without talking to him about it. . . .[I]f he doesn't have to buy in [to a decision], then it's going to be a lot harder for me to deal with that decision and getting it to be accepted and make it happen. . . . [H]e knows . . . if there's something he wants to do, he can come and . . . we can talk it through. Is it realistic? Sometimes it is, sometimes it isn't."

A mother who uses supported decision making with her son said: "He's a human being. He has likes and dislikes; we all do. And why do we not respect that?"

Additionally, family members asserted that, because supported decision making tends to rely on natural supports, the people with disabilities using it will be engaged with their community, which will in turn enable them develop skills necessary to receive the information they need to weigh the benefits and risks of potential decisions. In addition, community members will hold each other accountable for the kind of support that is provided, which will also guard against conflicts of interest. For example:

- One family member said: "I do believe that's a better way to go when there is a group of people, because the way we supported [my son] is that we do build a circle of support around him so that people know and understand what his hopes and dreams are for the future."
- Another said: "[I]f you have supported decision-making and the person could still keep their rights, . . . if there's a small group of people [supporting the person], hopefully, they would hold each other accountable [and include] some family members so that . . . people [involved] have similar values. . . . I think there's some level of safety in that."

However, there were also those who expressed concern that third-party providers, such as doctors, may be less likely to listen to people with disabilities who are using supported decision making as opposed to their guardians. One interviewee remarked that, although learning decision making through experiences with it was important, supported decision making is not ideal for people who do not use verbal communication. Another participant also noted that supported decision making only works when everyone involved is open, honest, and believes in community. For example:

- "[I]f a person cannot speak up for themselves, how do we ensure that they have equity? How do we ensure that he is not just left sitting as he is in a corner in a chair alone 24 hours a day? Supported decision making won't take care of that."
- "I really hate saying [this] because I think everyone can make decisions on some level. But [for] some of the very larger ones . . . we know that she is unable to process all of that."

"I think supported decision-making can be alternative outside of guardianship as well as a component within an appropriate . . . guardianship."

Professionals

NCD's research found that professional experts expressed positive, negative, and neutral reactions regarding supported decision making as a viable alternative to guardianship.

Positive responses considered supported decision making the "gold standard," part of what it means to become an adult, and an empowering way to maximize autonomy, self-control, and self-esteem. Some saw supported decision making as a way people can make decisions consistent with their own goals and values and lead happier and healthier lives. Others commented:

- "I think supported decision-making can be alternative outside of guardianship as well as a component within an appropriate . . . guardianship."

- "That's what we should be focused on, that no one is ever truly independent. We're interdependent on one another and that's true for people with all kinds of disabilities and people without disabilities."

Negative responses about supported decision making noted that it, as well as other alternatives to guardianship, such as powers of attorney and representative payees, still affords opportunities for abuse and exploitation. For example:

- "I'm not sure that . . . supported decision-making is going to make a difference one way or the other in terms of preventing . . . abuse. . . . We want to allow people to make mistakes and to be like everybody else but sometimes the cost to somebody with a disability is . . . being abused and taken advantage of . . ."
- "Well, frankly, I don't know that anybody knows what [supported decision-making] exactly means. . . . [Y]ou're to get . . . people around this person and then you support what their decisions are and . . . , unless the person has only the physical disability, I think that's pretty stupid. Now that doesn't mean we don't do supported decision-making all the time as a guardian, [but] we have some controls over that [to be sure about] what makes them safe and what might . . . put them at risk . . . We don't do [something] just because they say [so] because, at the end of the day, if we help facilitate somebody doing something that puts them at risk and they get hurt, guess who's liable? Me."

They also raised concerns about supporters imposing their own beliefs on the person.

- With supported decision making, "what you're supposed to do is help facilitate the person to make their own decision, but if your facilitator has very strong belief about what this person should or not be doing, it's hard to imagine how they're going to be a very effective facilitator."

Neutral reactions included calls for training on supported decision making and more safeguards against abuse and exploitation. It was also noted that parents may find it particularly difficult to transition to allowing their adult child to use supported decision making.

Access to Information About the Guardianship Process and Possible Alternatives

NCD's research identified two salient and overarching themes regarding whether people with disabilities and their families are being provided with information about the guardianship process and possible alternatives. These themes are as follows:

- People with disabilities, family members, and professionals agree there is not enough high quality and accessible information available about alternatives to guardianship, particularly supported decision making. Often, people are presented with guardianship as the only option.
- While many people are not familiar with supported decision making as a formal concept, they are engaging in it and benefiting from it.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD's research found that people with disabilities subject to guardianship expressed positive and neutral reactions regarding information about guardianship and its alternatives.

There were people subject to guardianship who responded that their guardian provides them with information as needed. For example:

- One person, who was in his mid-50s, has an acquired brain injury and hearing impairment, and whose sister serves as his guardian, stated: "I like having a guardian . . . They look after me and take good care of me, make sure I'm doing nothing wrong and make sure I'm taking my medicine . . . They make sure that everything I do I go the right [way] in doing it and . . . make sure that I'll be happy. I have no complaints about the way they treated me."

Many respondents reported that they were not familiar with alternatives to guardianship or did not know whether they were ever offered or explained.

People with disabilities using alternatives to guardianship

NCD research found that people with disabilities using alternatives to guardianship expressed positive, negative, and neutral reactions regarding the receipt of information about guardianship and its alternatives. Some interviewees had received information about guardianship and its alternatives through the school system or community-based programs. Others did not specify how they learned about guardianship and its alternatives.

Negative reactions called for more personalized education and training on decision making and money management for people with disabilities, their supporters, the educational system, and the broader community. Some saw the educational system as pushing parents into becoming guardians without informing them of other options. For example:

- "[P]arents are told that when their child turns 18 and they don't have a guardian, they won't be able to make medical decisions, they . . . won't be able to support their loved ones. So, you got a lot of parents that . . . will then rush to go get guardianship and then, once they get it, and they actually realize, 'Oh, my goodness, my son or daughter no longer has rights,' then they can't get that overturned."

So, you got a lot of parents that . . . will then rush to go get guardianship and then, once they get it, and they actually realize, 'Oh, my goodness, my son or daughter no longer has rights,' then they can't get that overturned."

Family member guardians and/or supporters

NCD research found that family members and supporters received a range of information about guardianship and its alternatives. Some learned about decision making options, such as supported decision making, power of attorney, and representative payee, through case managers, community programs, and their own

jobs. Others only received information about guardianship from their child's school or legal professionals and were never presented with options other than guardianship. For example:

- "[T]he information does not come to families or individuals. You have to go seek it out yourself and I think that's part of, I think there's just a lot of misinformation and no information."
- "I would love to get out of guardianship but have been unable to. . . . We received guardianship when she was 18 because we were told that was the right thing to do. . . . I was told that because [my daughter's disability] is so severe and she's also nonverbal . . . that we should assume guardianship for her at the age of 18, and this was by the school . . . I think that parents who made decisions years ago without options should now . . . be able to go back and have the opportunity that parents have now of putting one of less-restrictive options into effect."
- "[M]y husband and I questioned, 'Why do we need to get guardianship? We will always see that he's cared for properly and all of that,' but [we were told] that was the practice."

Some reported that they had been engaging in supported decision making, but were not familiar with the term. Others expressed concern about the potential for there to be abuse and exploitation outside of guardianship. Others described applying supported decision making in select situations. For example:

- One guardian said: "When it's appropriate I ask what [my daughter's] choice is and go with her choice. . . . When it's over her head and she won't be able to comprehend a decision, then we make it for her in her best interest."

Professionals

NCD's research found that the professionals interviewed also had a range of positive, negative, and neutral responses regarding information about guardianship and its alternatives.

"I think that parents who made decisions years ago without options should now . . . be able to go back and have the opportunity that parents have now of putting one of less-restrictive options into effect."

Some professionals asserted that the public is generally aware of both limited and full guardianship and that many learn about it through their peers and affiliations with organizations knowledgeable about it, so there is a need for self-advocacy. Others felt that information on decision making processes was inadequate or nonexistent, and that such information should be presented not only in legal settings, but also schools and health settings.

- One professional indicated that guardianship was the main option presented to families of people with developmental disabilities: "When your child is 18 years old, you had better be in court and getting that guardianship, bingo bango, just like that."

Other professional experts remarked that information dissemination varies from case to case and state to state.

Impact of Guardianship

NCD research identified two salient and overarching themes from the interviews with respect to the impact that guardianship has on people with disabilities and their families.

- Guardianship can be overly restrictive in its effect.
- Guardianship can improve the lives of those supporting the person with disabilities, but it does not necessarily improve the life of the person subject to guardianship.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

NCD research found that people with disabilities subject to guardianship had positive, negative, and neutral reactions to how guardianship impacts them and their families and improves health and safety outcomes.

Some interviewees described positive experiences in which their guardians assisted them in managing their finances, answered their questions, or protected them from making poor decisions. For example:

- One person, who was in her early 60s and had a psychosocial disability, reported liking her public guardian: "They help me with my money and stuff and make sure that my bills are paid and stuff like that." She went on to say: "I said, 'I don't want nobody to take advantage of me no more.' I said, 'I'm safer with you, [Public Guardian].' I told her that she is an angel from heaven and she is." She also explained how her guardian helped her get some of her rights restored.

Others felt negatively or neutral about being subject to guardianship. One person felt that guardianship led people to underestimate their intelligence. Another did not feel any significant change to his or her life since being subject to guardianship.

"[I]t was a real eye-opener when I got to ask my wife, 'Would you marry me?' I didn't have to go to my mom [to get permission] and say, 'Hey, ma, I asked that girl, will she marry me?'"

People with disabilities using alternatives to guardianship

People with disabilities using alternatives to guardianship had negative and neutral reactions to how guardianship impacts people and their health and safety.

Many interviewees disliked the lack of control people have over their decisions and finances when they are subject to guardianship. For example:

- One man with a developmental disability described the self-worth that came from making his own decisions: "[I]t was a real eye-opener when I got to ask my wife, 'Would you marry me?' I didn't have to go to my mom [to get permission] and say, 'Hey, ma, I asked that girl, will she marry me?'"
- A woman in her 20s said: "I felt very uneasy over the idea of someone else having

control of my life. . . . It makes me feel sad, and sometimes even irritated, because the guardian can always make decisions for the person, and what if the person wants something different than what the guardian wants? . . . I would feel kind of like a prisoner, knowing that all my decisions were up to someone else."

One interviewee recounted that, when she was subject to guardianship, she was psychologically, verbally, and physically abused by staff at a hospital. She went on to say that, to her, guardianship "means prison on the outside of the prison."

Another interviewee shared that she felt that being subject to guardianship has an effect on a person's development of decision making ability: "I think [my friend who is subject to guardianship] has trouble making her own decisions because she always just seems to go with what her guardian wants, and never really seems to question it."

Neutral responses noted that the impact of guardianship varies case by case.

Family member guardians and/or supporters

Family members and/or supporters had positive, negative, and neutral reactions to how guardianship impacts people and their health and safety.

Positive reactions included assertions that that guardianship means there will be court oversight, which will provide the people subject to it some protection from exploitation. Others noted that guardianship gives the guardians themselves greater peace of mind. For example:

- "[W]e had a major incident and went to the hospital. And the hospital said that they would give all the information [about my brother] to the [residential] provider about what happened and they would not give that information to me . . . It was part of the reason I took guardianship."
- "I have legal guardianship over my son but it's just there. It's just sitting there on a shelf. . . . [I]t's just there as a safety net . . . So, I can sleep more soundly knowing that . . . the police couldn't come to my door, take him away in handcuffs and not have to speak to me."

"I have legal guardianship over my son but it's just there. It's just sitting there on a shelf. . . . [I]t's just there as a safety net . . . So, I can sleep more soundly knowing that . . . the police couldn't come to my door, take him away in handcuffs and not have to speak to me."

Others saw guardianship as a way of supporting the decision making of the person subject to it, while allowing the guardian to act on the person's behalf in the event he or she is incapable of making a certain decision. For example:

- One family member guardian stated: "I first of all make sure that people speak to [my son, who has a traumatic brain injury], because often, because he doesn't speak, people assume that he's not bright enough to understand and that they address me, because I'm his guardian. And . . . as a human being, he has a right to be addressed . . . and not spoken about [but] spoken to."

Many negative responses argued that neither guardianship nor any support system can totally protect a person from exploitation, and that the lack of checks and balances within guardianship can actually foster exploitation and abuse. For example:

- "My daughter is just as safe even if I didn't have guardianship. I'm still her mother and there's still people in the community that were looking after her with or without guardianship. I don't think guardianship makes any difference on your safety. Just having that piece of paper doesn't make you safer."
- "[My daughter] says you can [try and] bubble wrap people, but that's still not going to stop them from getting into trouble. . . . Sometimes those things just happen. [Your] piece of paper that says [you have a] guardian isn't going to stop things."
- "Guardianship is not going to be a bubble around you that protects you completely. . . . The problem with guardianship, in general, is the extent of authority that people do have over other people and the potential for exploitation and abuse . . . [T]here have been some gosh awful stories about guardians [and others] who . . . exploit. They take . . . [people's] government benefits or whatever other money, and they lock people in . . . a closet and don't take care of them."
- "[G]uardianship can make people more vulnerable. . . [T]here's a possibility that others might find that person more vulnerable if they knew that somebody else was somewhat overseeing their decision making or their health or anything like that. I think it puts them in a more vulnerable position."

Many saw guardianship as negatively impacting people's health and happiness and forcing them to live the lives the guardians wanted for them. " For example:

- "It's going to be about what's best for the agency or the guardian and that's not necessarily the best for the person."
- "Actually, what I know now is that she's not [considered by others to be] a real person anymore, that she really doesn't exist except for what I allow her to have and what I allow her to do, . . . as a guardian."

"Actually, what I know now is that she's not [considered by others to be] a real person anymore, that she really doesn't exist except for what I allow her to have and what I allow her to do, . . . as a guardian."

Neutral responses reported that the pros and cons of guardianship vary on a case by case basis. For example:

- "[I]t can be good and it can be bad. It all depends on the guardian. If . . . there had been people that had been [subject to] guardianship because they're in very poor health, because they haven't been taking their medicine or whatever, and once they get the guardian in place, and when they get the health fund[ed], they can restore their lives."

Professionals

Professional experts had positive, negative, and neutral reactions to how guardianship impacts people and their health and safety.

There were professionals who asserted guardianship ensured people subject to it had their needs met; were protected from exploitation and abuse; and were served by outside providers, such as those in health care, housing, and finance arenas. For example:

- "[T]here are lots of situations where guardianship or conservatorship is absolutely wanted and I think to take that tool away would be bad for a bunch of different reasons."
- "[S]ome people are very happy to get the help. They know they can't handle things anymore and they're cooperative."
- "[W]hen a guardianship is appropriate is when a person . . . is putting themselves at serious risk or being financially exploited. For somebody who is financially exploited, oftentimes the guardianship is the only way to protect them. . . . I've gotten some self-neglect cases . . . [where] one person was almost dead by the time they were removed from the house and another had a long history of signing himself out AMA from various facilities and such. . . . [I]f we are looking at people who are putting themselves at risk and not open to any other options . . . the only choice is guardianship."
- "I can't give you case examples but I would say that most guardianships provide positive outcomes for the individual . . . We don't have the data [but] it's [likely] a miniscule percentage of the overall number of guardianship cases that are problematic."

Others saw guardianship as improving the lives of those surrounding the person with disabilities without necessarily improving his or her own life. For example:

- "[T]he threat of guardianship . . . if you have problems because of cognitive impairment, the help you're going to get is, 'We're going to take away your rights.' That causes a lot of people to absolutely deny that they have a problem to accept any help when the problem might be much more easily managed."
- "[I]f I get a guardianship, I don't have to argue with mom anymore about whether she should move or . . . whether she can still drive or whatever. I don't have to argue with her anymore. I can just tell her."
- "I think guardianship can be an effective tool for some people . . . [I]t's simpler to have guardianship. It's more complicated to have conversations."

"I think guardianship can be an effective tool for some people . . . [I]t's simpler to have guardianship. It's more complicated to have conversations."

Negative reactions stated that guardianship does not eliminate abuse, but can generate hostility, dehumanize and disempower people subject to it, and negatively impact

family relationships and natural supports. For example:

- One professional with a background in long-term care and adult guardianship through a state division of aging services said: "[I]t doesn't make sense to me that you take rights away from an individual to help them." She went on to say: "I've run into quite a few people [subject to guardianship] who have said, 'I am not a person anymore.'"
- An attorney, law professor, and consultant on disability-related issues said: "[G]uardianship creates a category of people who are not considered as legal people." She went on to say: "I don't think people are going to necessarily be exploited or hurt if there is no guardianship anymore. People are exploited and hurt right now with guardianship. Let's try a different way." She noted that guardianship could also detrimentally impact decision making skills of youth with disabilities: "When guardians are appointed for someone with an intellectual disability at the age of 18, they are denied the opportunity to learn how to make decisions of the critical years of their lives."
- Another added: "I think it is a terrible affront to human dignity to take away somebody's ability to make basic life decisions and cut them out of the conversation, if they are able to participate in any way."

Others pointed to the fact that abuses can occur within guardianship:

- One interviewee stated: "[W]ith guardianship . . . you always have the potential for somebody to abuse their powers. . . . You can have an incredibly protective parent that gets a guardianship and is convinced that [example person] can never cross the street so [example person] doesn't flourish and grow . . ."
- Another participant, who was part of a service provider for people with developmental disabilities stated: "[P]eople have sort of succumbed to the power of the guardianship that made terrible choices for people. They've ripped people off, neglected people, have isolated people, and so I've seen the worst kinds of guardianships . . . ."
- An attorney for a public guardian agency described abusive guardianship situations in which her office was asked to intervene: "[In] many other cases [we] were brought [in] where there's an existing guardian [that] either somehow failed to complete their duty [or] they misappropriated money or they didn't do what they were supposed to do and they've neglected the person or abused the person in some way."

"[I]t doesn't make sense to me that you take rights away from an individual to help them."

Neutral reactions contended that any support system requires a process for ensuring there are no conflicts of interest.

National Disability Policy Goals and Initiatives

NCD's research identified two salient and overarching themes from the interviews with

respect to the impact that guardianship has relating to U.S. national disability policy goals and initiatives:

- Good guardians support and advocate for people subject to guardianship in ways that align with disability policy goals.
- Guardianship can also inhibit an individual from living a full, integrated life.

The analysis results for each participant category are discussed as follows.

People with disabilities subject to guardianship

People with disabilities subject to guardianship had positive, negative, and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives.

Multiple people subject to guardianship reported that guardianship did not impact their day-to-day lives, where they lived, or their community involvement. Others disagreed. For example:

- Guardianship is "a lot different from what I thought. I thought . . . they would just help us handle our money and everything, [but] we are in servitude to them with their workers. . . . I don't mind a little help . . . , but when they control my life every day, tell me where to go, what time, when to shave, when not to shave . . . I do not like this guardianship."

"I thought . . . they would just help us handle our money and everything, [but] we are in servitude to them with their workers. . . . I don't mind a little help . . . , but when they control my life every day, tell me where to go, what time, when to shave, when not to shave . . . I do not like this guardianship."

People with disabilities using alternatives to guardianship

People with disabilities using alternatives to guardianship had negative and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives. Interviewees stated that guardianship impacts where people subject to it can live, what they can do, who they can associate with, how they are treated, and how integrated into the community they are. For example:

- "Well, it's good because . . . I'm still living by myself, choose who to come and who not to come and I still being able to choose what I want to eat, when I want to eat it . . . So, my life, it's just like everyone else's right now."
- "Sometimes, when we protect people, we shelter them. So this is why I say, sometimes guardianship can be a hindrance because we never give somebody the chance to make even the small decisions from what they want to eat or what they want to wear. Then, you run the risk of them never ever being able to make a decision."

Neutral responses asserted that all forms of decision making requires varying levels of support depending on the extent of the person's disability.

Family member guardians and/or supporters

Family members and/or supporters had positive, negative, and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives.

Some expressed that guardianship supported people's civil rights and ensured they are safe and can build decision making skills. For example:

- "Our job as guardian was to keep him safe, and to help him grow to where he could make decisions on his own with support."

"Our job as guardian was to keep him safe, and to help him grow to where he could make decisions on his own with support."

Others indicated that they supported the person with disabilities to choose for themselves where they lived, what they wanted to do, whether and how they wanted to vote, and whether or not they wanted to get married.

A number of interviewees described guardianship as an invasion of civil and human rights that creates stigma, lowers expectations, and negatively impacts how others act toward people with disabilities. There were participants who asserted that people subject to guardianship are hindered from living a full life that is integrated within the community. For example:

- "I don't think anyone should have guardianship. I think everyone deserves civil rights no matter what your level of understanding is. I assumed because my daughter is nonverbal, I have to assume that she understands everything and I think that's how we should think of everyone."
- "[T]he idea of me declaring him incompetent is kind of the opposite of everything we're striving for . . . [D]eclaring someone to be incompetent takes away their personhood and in a sense makes them a piece of property."
- "[G]enerally speaking, the public is still paternalistic and maternalistic towards people [subject to] guardianship. 'Oh, you poor little person, you've got [a disability], you can't do this and you can't do that, and yadda, yadda, yadda.'"

"[T]he idea of me declaring him incompetent is kind of the opposite of everything we're striving for . . . [D]eclaring someone to be incompetent takes away their personhood and in a sense makes them a piece of property."

Neutral responses recognized that the experiences of people subject to guardianship can vary—some can be empowered and others can be disempowered by it.

Professionals

Professional experts had positive, negative, and neutral reactions to how guardianship currently aligns or conflicts with national disability policy goals and initiatives.

Some interviewees argued that guardianship aligns with disability policy goals in that good

guardians support and advocate for the person in a way that helps him or her be integrated. For example:

- "The good guardian is going to ensure that there is integration into the community[,] . . . that they receive the socialization, the community interaction, the community respect that they are do and that's what a good guardian does."

Other interviewees asserted that guardianship impinges on a person's civil rights, correlates with social isolation, and as a result conflicts with disability policy goals, such as the ADA. For example:

- "By definition, if you are not the person making decisions, your ability to be a real member of the community [is] smaller . . . [I]n most instances, guardianship violates the inclusion mandate of the ADA and the *Olmstead* principle."
- "[Guardianship is] never going to allow that person [subject to it] to really become integrated to community because [others are] going to have to be always checking" with the guardian, not the person.

A neutral reaction noted that focusing on the dignity and autonomy of people with disabilities can fix the problems of guardianship and inequality faced by that population.

Chapter 10: Findings and Recommendations

Throughout this report NCD has noted that while guardianship exists to protect individuals who may need assistance managing their affairs or who may need protection from abuse, neglect, or exploitation, it also undermines the ability of people with disabilities to exercise self-determination often without sufficient due-process to say definitively that the individual lacked the capacity to make decisions for themselves. Additionally, in some cases, guardianship may create conditions that lead to exploitation rather than protecting vulnerable individuals from it. As NCD examined the ongoing efforts of the past several decades to rectify some of the well-recognized problems in guardianship, it became clear there are no easy answers or perfect solutions to these complex issues. However, the Council makes the following findings regarding the current state of guardianship and offers recommendations that we believe would improve the lives of people with disabilities who may need decision making assistance and prevent them from being placed into unnecessary or overly restrictive guardianships as well as improving court oversight of existing guardianships to prevent abuse, neglect, and exploitation.

Finding 1: There is a lack of data on existing guardianships and newly filed guardianships.

Most states do not track on a statewide basis how many individuals are subject to guardianship, much less describe those guardianships in terms of basic demographic information, whether the guardian is a professional or family guardian, the extent of the guardian's authority, the assets involved, and other basic questions that would help policymakers and stakeholders make determinations about what reforms may be needed in guardianships or where resources should be directed to improve guardianship outcomes for people with disabilities.

(continued)

Recommendations:

NCD recommends that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship. There are two ways production of this data should be approached:

- Federal agencies such as the SSA, the CMS, the VA, SAMHSA, and other relevant agencies should collect data on whether or not individuals they serve are subject to guardianship.
- States should be offered incentives and technical assistance with developing electronic filing and reporting systems that collect basic information about guardianships from the moment a petition is filed. A searchable, computerized system for aggregating information on adult guardianship cases would not only yield better usable data on guardianships, but would also improve that ability of courts to monitor and audit individual guardianships. Systems such as the "My Minnesota Conservator" reporting and data project are already in use in a few states and could be adopted across the country. Data collected must be detailed enough to allow for drawing conclusions and should include demographics, type of guardianship (limited vs. plenary, guardian over property vs. person, etc.), type of guardian (public guardians, private professional guardian, family guardian), age at which the person was subject to guardianship, court audits, timeliness of reports, amount of funds/property in the estate, and the involvement of the person in federal programs (Social Security benefits, SSI, Medicaid, Medicare, VA benefits, etc.). The data should also include whether the initial petition was contested, whether there is any time limitation to the guardianship, and whether there is any periodic review of the continued need for guardianship.

Finding 2: People with disabilities are widely (and erroneously) seen as less capable of making autonomous decisions than other adults regardless of the actual impact of their disability on their cognitive or decision making abilities. This can lead to guardianship petitions being filed when it is not appropriate and to guardianship being imposed when it is not warranted by the facts and circumstances.

Recommendations:

- The DOJ, in collaboration with the HHS, should issue guidance to states (specifically Adult Protective Services [APS] agencies and probate courts) on their legal obligations pursuant to the ADA. Such guidance should address NCD's position that: 1) the ADA is applicable to guardianship proceedings; 2) the need for assistance with activities of daily living or even with making decisions does not give rise to a presumption of incapacity; and

(continued)

3) guardianship should be a last resort that is imposed only after less restrictive alternatives have been determined to be inappropriate or ineffective.

- In January 2017, the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) issued school-to-adult transition-related guidance that recognized alternatives to guardianship, including the use of supported decision making and powers of attorney for adult students with disabilities. While this policy development is promising, OSERS needs to do more to ensure consistent implementation of this guidance across state and local educational agencies—for example, the creation of model supported decision making and powers-of-attorney forms geared toward transition-age youth. School transition teams must inform parents/caregivers and students of less-restrictive decision making support options for adults, rather than promoting the overuse of guardianship or involuntary educational representatives.
- The Department of Education Office of Special Education Programs (OSEP) should instruct Parent Training and Information Centers to prioritize and provide meaningful training on school-to-adult transition and alternatives to guardianship.
- HHS should issue guidance regarding the responsibility of medical professionals and hospitals to accommodate the needs of individuals who may need assistance making medical decisions and to adequately explain procedures and draft documents provided to patients in plain language.
- Although the Federal Government generally leaves the content of medical school training to the accrediting bodies, federal advisory group recommendations and federal grants from CMS, HHS, and other federal agencies can influence the content of medical training and curriculum. Educating medical professionals about the ADA and the need to accommodate people with disabilities, including those with intellectual disabilities and cognitive impairments, should be prioritized as a part of medical training.
- The National Home and Community-Based Services Quality Enterprise (NQE) should include decision making assistance and use of alternatives to guardianship such as supported decision making in their priorities and include best practices as part of its resources, training, and technical assistance.
- The Administration for Community Living (ACL) has funded numerous projects that are geared toward expanding alternatives to guardianship, such as supported decision making. The agency also provides state grants to enhance adult protective services. Such funding should be allocated specifically to assist state adult protective services systems to develop greater awareness of ways to enhance the self-determination of adults considered vulnerable or in need of services, as well as the availability and use of alternatives to guardianship.

(continued)

- The Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities (UCEDDs), and the Protection and Advocacy (P&A) organizations should link work that has been done on advancing the self- determination of people with ID/DD with avoiding guardianship. There needs to be recognition that the appointment of guardians is not necessarily the preferred outcome for people with disabilities. Such appointments instead can be the result of systems failing to fully recognize people's right to direct their own life and to support them in developing self-determination and communication skills, use and build natural support networks, and have access to less-restrictive alternatives. . UCEDDs in particular have a role in educating physicians, medical professionals, and parents of people with ID/DD on self-determination, SDM, and other alternatives to guardianship.

Finding 3: People with disabilities are often denied due process in guardianship proceedings.

Guardianship is viewed as a benevolent measure that is sought in the best interest of people with disabilities and/or older adults who are seen as needing protection. Guardianship cases are often dispensed with as quickly as possible with little concern for due process or protecting the civil rights of individuals facing guardianship.

Recommendations:

- The Elder Abuse Prevention and Prosecution Act (P.L. 115-70) calls upon the Attorney General to publish best practices for improving guardianship proceedings and model legislation relating to guardianship proceedings for the purpose of preventing elder abuse. The Attorney General's model legislation should incorporate the UGCOPAA, including its provisions for preventing unnecessary guardianships.
- To ensure that due process requirements are met, it is especially important that alleged incapacitated individuals facing guardianship have qualified, independent legal representation that will advocate for the individual's desired outcome, especially if that person expresses a desire to avoid guardianship or objects to the proposed guardian. However, many courts lack sufficient resources to fund this type of representation and families often find that such representation is cost-prohibitive. Federal grant money should be made available to help promote the availability of counsel.

(continued)

- A state guardianship court improvement program should be funded to assist courts with developing and implementing best practices in guardianship, including training of judges and court personnel on due process rights and less-restrictive alternatives.
- The degree of due process provided in a guardianship matter should not be contingent on the type of disability that is the alleged cause of an individual's incapacity or inability to make and carry out decisions. The DOJ should take the position that such practices are discriminatory on the basis of the ADA.

Finding 4: Capacity determinations often lack a sufficient scientific or evidentiary basis.

Courts rely too heavily on physicians who lack the training, knowledge, and information needed to make an accurate determination.

Recommendations:

- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), National Institutes of Health, and other agencies that fund scientific research should provide grants to researchers who are trying to develop a better understanding of how people make decisions and how a variety of conditions—such as dementia, intellectual disabilities, brain injuries, and other disabilities—impact the ability of individuals to make and implement informed decisions.
- *Capacity* is a social and legal construct that is not necessarily provable or disprovable through scientific methods. Resources also should be geared toward developing functional approaches to capacity assessments that take into account the possibility that someone may need decision making assistance but not necessarily a surrogate or substitute decision maker.

Finding 5: Guardianship is considered protective, but courts often fail to protect individuals.

In some cases, guardians use their position to financially exploit people or subject them to physical neglect and abuse. Courts lack adequate resources, technical infrastructure, and training to monitor guardianships effectively and to hold guardians accountable for the timely and accurate submission of required plans, accountings, and other reports, as well as for conforming to standards of practice for guardians.

(continued)

Recommendations:

- The court improvement program proposed earlier could also enhance the ability of courts to monitor guardianships and should include the adoption of programs such as My MNConservator, which requires guardians to file reports electronically, allows for the flagging potential problems in filed accountings, and facilitates the periodic audit of guardianship files.
- Although professional and family guardians can both be the perpetrators of abuse in guardianship, there have been several high-profile cases of abuse by professional guardians. In most states, these professionals operate with minimal oversight except by the court. States should be provided with incentives to establish statewide boards that can provide for the accreditation and oversight of professional guardians.
- States should require family guardians to undergo training to ensure they understand their ongoing responsibilities to the person subject to the guardianship and to the court.

Finding 6: Most state statutes require consideration of less-restrictive alternatives, but courts and others in the guardianship system often pay lip service to this requirement.

Courts often find that no suitable alternative exists when, in fact, supported decision making or another alternative might be appropriate.

Recommendations:

- ACL currently funds the National Resource Center for Supported Decision making and several demonstration projects at the state and local levels. These grants should be expanded to be able to fund more geographically- and demographically-diverse projects and pilots that specifically test SDM models and use SDM and the court systems to restore people's rights as a matter of law, particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.
- The DOJ should make funding available to train judges in the availability of alternatives to guardianship including, but not limited to, supported decision making. This training should also include information about the home and community-based–services system and the workforce development system so that judges understand the context in which decisions are being made by and for people with disabilities. See Finding 3.
- It's important that states adopt provisions of the UGCOPAA that recognize alternatives to guardianship can be used in place of guardianship even when it is determined that the individual meets the definition of incapacity. DOJ should develop guidance to this effect.

Finding 7: Every state has a process for restoration, but this process is rarely used and can be complex, confusing, and cost-prohibitive.

Data on restorations is seriously lacking, making it impossible to tell how many individuals are in unnecessary guardianship or whether individuals who would like to try to have their rights restored have access to information about their right to restoration, receive an appropriate response to their request for restoration, or have access to resources and representation to assist them in that effort.

Recommendations:

- As a part of the effort to improve data collection and monitoring, electronic filing and auditing systems ought to include data about restoration, including whether the individual was given information about restoration and whether the continued need for guardianship was reviewed by the court.
- The state court improvement program referenced throughout these recommendations should include improvements to the restoration process. DOJ should publish guidance regarding the right to restoration and best practices.
- A grant should be given to the Protection and Advocacy system to provide legal assistance to individuals who are trying to have their rights restored or avoid guardianship.

Appendix A: Table of Authorities—State Guardianship Statutes

AL	Ala. Code. T. 26, Ch. 2A, Art. 1-2	MT	Mont. Code Ann. T. 72, Ch. 5, Pt. 1-6
AK	Alaska Stat. Ann. T. 13, Ch. 26, Art. 1-6	NE	Neb. Rev. Stat. Ch. 30, Art. 26, Pt. 1-5
AZ	Ariz. Rev. Stat. T. 14, Ch. 5, Art. 1-8	NV	Nev. Rev. Stat. Ann. T. 13, Ch. 159
AR	Ark. Code. Ann. T. 28, Subpart 5, Ch. 74 Art. 1-5	NH	N.H. Rev. Stat. Ann. T. XLIV, Ch. 462-465
CA	Cal. Prob. Code §§ 1400-1490; 1500-1611; 1800-1970; 2100-2893; 2900-2955.	NJ	N.J. Stat. Ann. T. 3b, Ch. 12, Art. 4-7
CO	Colo. Rev. Stat. Ann. T. 15, Art. 14, Pt. 1-5	NM	N.M. Stat. Ann. Ch. 45, Art. 5, Pt. 1-4
CT	Conn. Gen. Stat. Ann. §§ 45a-591 to -602; 45a-628 to -705a	NY	N.Y. Mental Hyg. Law §§ 81.01 to 81.44; N.Y. Soc. Serv. Law §§ 473-d to -e
DE	Del. Code Ann. T. 12, Ch. 39, Subpart I-VII	NC	N.C. Gen. Stat. Ann. Ch. 35A, Subch. I-IV
FL	Fla. Stat. Ann. T. XLIII, Ch. 744, Pt. I-VIII	ND	N.D. Cent. Code Ann. T. 30.1, Art. V, Ch. 30.1—28
GA	Ga. Code Ann. T. 29, Ch. 1-11	OH	Ohio Rev. Code Ann. Sup. Rule 51, Form 15
HI	Haw. Rev. Stat. T. 30A, Ch. 560, Art. V, Pt. 1-6	OK	Okla. Stat. Ann. T. 30, Art. 3
ID	Idaho Code Ann. ST. T. 15, Ch. 5, Pt. 1-6	OR	Or. Rev. Stat. Ann. T. 13, Ch. 125, Art. 1-5
IL	Ill. Comp. Stat. Ann. Ch. 755, Act. 5, Art. XIA	PA	Pa. Cons. Stat. Ann. T. 20, Ch. 55, Subch. C-F
IN	Ind. Code Ann. T. 29, Art. 3, Ch. 1-13	RI	R.I. Gen. Laws Ann. T. 33, Ch. 15.2
IA	Iowa Code Ann. T. XV, Subpart 4, Ch. 633, Div. XIII, Pt. 1-7	SC	S.C. Code Ann. T. 62, Art. 5, Pt. 1-7
KS	Kan. Stat. Ann. Ch. 59, Art. 30	SD	S.D. Codified Laws T. 29a, Ch. 29A-5, Pt. 1-5
KY	Ky. Rev. Stat. Ann. T. XXXIII, Ch. 387	TN	Tenn. Code Ann. T. 34, Ch. 1-8
LA	La. Rev. Stat. Ann. T. 13, Ch. 24, Pt. I-V	TX	Tex. Est. Code T. 3, Subt. D-I
ME	Me. Rev. Stat. T. 18-a, Art. V, Pt. 5-a, Subpart 1-5	UT	Utah Code Ann. T. 75, Ch. 5, Pt. 1-6
MD	Md. Code Ann. T. 13, Subpart 2 & 7, Pt. II	VT	Vt. Stat. Ann. T. 14, Pt. 4, Ch. 111
MA	Mass. Gen. Laws Ann. T. 2, Ch. 190B, Art. V-5a	VA	Va. Code Ann. T. 37.2, Subt. IV, Ch. 10-10.1
MI	Mich. Comp. Laws Ann. Ch. 700, Art. V, Pt. 1-5	WA	Wash. Rev. Code Ann. T. 11, Ch. 11.88-11.92

(continued)

MN	Minn. Stat. Ann. Ch. 252A	WV	W. Va. Code Ann. Ch. 44A, Art. 1-5
MS	Miss. Code. Ann. T. 93, Ch. 14, Art. 1-5	WI	Wis. Stat. Ann. Ch. 54, Subch. I-VII
MO	Mo. Ann. Stat. T. XXXI, Ch. 475	WY	Wyo. Stat. Ann. T. 3, Ch. 2, Art. 1-3
DC	D.C. Code Div. III, T. 21, Ch. 20, Subpart I-VI		

Appendix B: Developmental Disability Specific Guardianship Statutes

AZ	Ariz. Rev. Stat. T. 36, Ch. 5.1, Art. 1	KY	Ky. Rev. Stat. Ann. T. XXXIII, Ch. 387.550-387.880
CA	Cal. Health & Safety Code Div. 1, Pt. 1, Ch. 2, Art. 7.5	MI	Mich. Comp. Laws Ann. Ch. 6, Sec. 330.1600-330.1644
CT	Conn. Gen. State Ann. §§45a-669 to -684	MN	Minn. Stat. Ch. 252A, Sec. 252a.01-252a.21
FL	Fla. Stat. Ann. T. XXIX, Ch. 393	NY	NY Surr. Ct. Pro. Act Law Ch. 59-a, Art. 17-a Sec. 1750
ID	Idaho Code Ann. T. 66, Ch. 4	SD	S.D. Cod. Laws T. 29A, Ch. 29A-5, Pt. 1-5
IA	Iowa Code Ann. T. XV, Subt. 4, Ch. 633, Div. XIV, Pt. 1		

Appendix C: Contact Information for WINGS Groups*

ACL Project WINGS	
Alabama	Bob Maddox; bob.maddox@alacourt.gov
Alaska	Stacey Marz; smarz@akcourts.us
Florida	Tina White; whitet@flcourts.org
Idaho	Nanci Thaemert; nthaemert@idcourts.net
Indiana	Erica Costello; erica.costello@courts.IN.gov
Oregon	Bryan Marsh; Bryan.B.Marsh@ojd.state.or.us
Utah	Karolina Abuzyarova; karolinaa@utcourts.gov
SJI Supported WINGS 2013	
New York	Jean Callahan; JCallahan@legal-aid.org
Oregon	Bryan Marsh; Bryan.B.Marsh@ojd.state.or.us
Texas	David Slayton; David.Slayton@txcourts.gov
Utah	Karolina Abuzyarova; karolinaa@utcourts.gov
SJI Supported WINGS 2015	
District of Columbia	Anne Meister; anne.meister@dcsc.gov
Indiana	Erica Costello; erica.costello@courts.IN.gov
Minnesota	Anita Raymond; araymond@voamn.org
Mississippi	Desiree Hensley; desiree.c.hensley@gmail.com
Washington	Stacey Johnson; Stacey.Johnson@courts.wa.gov
Additional WINGS-Type Groups*	
Maryland	Nisa Subasinghe; Nisa.Subasinghe@mdcourts.gov
Massachusetts	Wynn Gerhard; wgerhard@gbls.org
Missouri	Dolores Sparks; dsparks@moddcouncil.org
Montana	Sarah McClain; smcclain@mt.gov
North Carolina	Linda Kendall Fields; lkfields@email.unc.edu
Pennsylvania	Cherstin Hamel; Cherstin.Hamel@pacourts.us
West Virginia	Jennifer Taylor; jtaylor@lawv.net
Wisconsin	Andrew Bissonnette; bissonnetteandrew@yahoo.com
Virginia	Paul DeLosh; pdelosh@vacourts.gov

*Georgia, Guam, and Ohio also have WINGS-Type groups, but contacts for those groups were not readily available.

Appendix D: Attorney Representation in Initial Guardianship Cases

State	Entitlement to Appointment of Counsel in accordance with UGCOPA Sec. 305(a), Sec. 406(a)*		Statute specifies the advocacy role of Counsel in accordance with National Probate Court Standard 3.3.5(B)†	
Ala.	Yes	Code of Ala. § 26-2A-101(b); 26-2A- 135(b)	No	Code of Ala. § 26-2A-102(b); 26-2A-135(b)
Alaska	Yes	Alaska Stat. § 13.26.231	Yes	Alaska Stat. § 13.26.246
Ariz.	Yes	A.R.S. § 14-5303(c)	No	N/A
Ark.	Yes	A.C.A. § 28-65-213	No	N/A
Calif.	Yes	Cal Prob Code § 1823(b)(6); 1470(a); 1	No	N/A
Colo.	Yes	C.R.S. 15-14-305	No	N/A
Conn.	Yes	Conn. Gen. Stat. § 45a-649a; 45a-673; 45a-681	No	N/A
Del.	Yes	12 Del. C. § 3901(C)	No	N/A
D.C.	Yes	D.C. Code § 21-2041(d); 21-2054(a)	Yes	D.C. Code § 21-2033
Fla.	Yes	Fla. Stat. § 744.331	Yes	Fla. Stat § 744.102(1)
Ga.	Yes	O.C.G.A. § 29-4-11(c)(1)(D)	No	N/A
Hawaii	Yes	Haw. Rev. Stat. Ann. § 560:5-305.	No	N/A
Idaho	Yes	Idaho Code § 15-5-303(b)	No	Idaho Code § 15-5-303(b)
Ill.	Yes	755 Ill. Comp. Stat. Ann. 5/11a-10	No	N/A
Ind.	No	Ind. Code Ann. § 29-3-5-1.	No	N/A
Iowa	Yes	Iowa Code § 633.561.	No	N/A (but see *In re Guardianship of Griesinger*, 804 N.W.2d 527, 529 (Iowa Ct. App. 2011))
Kans.	Yes	Kan. Stat. Ann. § 59-3063.	No	N/A
Ky.	Yes	Ky. Rev. Stat. Ann § 387.560.	No	N/A
La.	Yes	La Code. Civ. Proc. Ann. Art. 4544.	No	N/A
Maine	Yes	Me. Rev. Stat. tit. 18-A, § 5-303	No	N/A
Md.	Yes	Md. Code Ann., Est. & Trusts § 13-705	No	N/A (but see *In re Lee*, 754 A.2d 426, 438-39 (Md. Ct. Spec. App. 2000)

(continued)

State	Entitlement to Appointment of Counsel in accordance with UGCOPA Sec. 305(a), Sec. 406(a)*		Statute specifies the advocacy role of Counsel in accordance with National Probate Court Standard 3.3.5(B)†	
Mass.	Yes	Mass. Gen. Laws ch. 190B, § 5-106.	No	N/A
Mich.	Yes	Mich. Comp. Laws Ann. § 700.5305, 700.5306a.	No	N/A
Minn.	Yes	Minn. Stat. Ann. § 524.5-304, - 307	No	N/A
Miss.	No	Miss. Code Ann. § 93-13-255.	No	Miss. Code Ann. § 93-13-255.
Mo.	Yes	Mo. Ann. Stat. § 475.075(3).	No	Mo. Ann. Stat. § 475.075(3).
Mont.	No	Mont. Code Ann. § 72-5-315(2)(4).	No	Mont. Code Ann. § 72-5-315(2).
Nebr.	No	Neb. Rev. Stat. Ann. § 30-2619	No	N/A
Nev.	Yes	Nev. Rev. Stat. Ann. § 159.0485.	No	N/A
N.H.	Yes	N.H. Rev. Stat. Ann. § 464-A:6.	No	N/A (but see In re Guardianship of Henderson, 838 A.2d 1277, 1278-79 (N.H. 2003))
N.J.	Yes	N.J.R. Super. Tax Surr. Cts. Acts. R. § 4:86-4 (b)	No	N/A (but see N.J.R. Super. Tax Surr. Cts. Acts. R. § 4:86-4 (b))
N. Mex.	Yes	N.M. Stat. Ann. § 45-5-303(C).	No	N.M. Stat. Ann. § 45-5-303(C).
N.Y.	No	No for people with IDD: N.Y. Surr. Ct. Proc. Act Law §§ 1750; 1750-a; 1750-b Yes for people without IDD: N.Y. Mental Hyg. Law § 81.10	No	N/A
N.C.	No	N.C. Gen. Stat. Ann. § 35A-1107.	No	N.C. Gen. Stat. Ann. § 35A-1107.
N. Dak.	Yes	N.D. Cent. Code Ann. § 30.1-28-03	No	N.D. Cent. Code Ann. § 30.1-28-03(4)(c)
Ohio	Yes	Ohio Rev. Code Ann. §§ 2111.02 (C)(7)	No	N/A (but see *In re Baby Girl Baxter*, 17 Ohio St.3d 229, 232 (1985) (superseded by statute on other grounds))
Okla.	Yes	Okla. Stat. Ann. tit. 30, § 3-106(A)(7), -107	No	N/A
Oreg.	No	Or. Rev. Stat. Ann. §§ 125.025; 125.080.	No	N/A
Pa.	Yes	20 Pa. Stat. and Cons. Stat. Ann. § 5511	No	N/A (but see *In re Estate of Rosengarten*, 871 A.2d 1249, 1257 (Pa. Super. Ct. 2005)
R.I.	Yes	R.I. Gen. Laws Ann. § 33-15-7.	No	N/A
S.C.	Yes	S.C. Code Ann. § 62-5-303(b).	No	S.C. Code Ann. § 62-5-303(b).

(continued)

State	Entitlement to Appointment of Counsel in accordance with UGCOPA Sec. 305(a), Sec. 406(a)*		Statute specifies the advocacy role of Counsel in accordance with National Probate Court Standard 3.3.5(B)†	
S. Dak.	Yes	S.D. Codified Laws § 29A-5-309	No	N/A
Tenn.	Yes	Tenn. Code Ann. § 34-1-125	Yes	Tenn. Code Ann. § 34-1-125(a)
Tex.	Yes	Tex. Est. Code Ann. § 1054.001	Yes	Tex. Est. Code Ann. § 1002.002
Utah	No	Utah Code Ann. § 75-5-303(2), (5)(3)	No	N/A
Vt.	Yes	Vt. Stat. Ann. tit. 14, § 3065	Yes	Vt. Stat. Ann. Title 14-3065(b).
Va.	No	Va. Code Ann. § 64.2-2006.	No	N/A
Wash.	Yes	Wash. Rev. Code Ann. § 11.88.045(a)	Yes	Wash. Rev. Code Ann. § 11.88.045(b)
W. Va.	Yes	W. Va. Code § 44A-2-7(a)	No	W. Va. Code § 44A-2-7
Wis.	Yes	Wis. Stat. § 54.42	Yes	Wis. Stat. § 54.42(b)
Wy.	No	Wyo. Stat. Ann. § 3-1-205(a)(iv)	No	N/A

* The UGCOPAA sets out two alternative counsel provisions: A) the court must appoint a lawyer to represent the respondent if 1) requested by the respondent, 2) recommended by the court visitor, or 3) the court determines it is needed; or B) unless the respondent is already represented by a lawyer, the court must appoint one.

† The National Probate Court Standards provide that "the role of counsel should be that of an advocate for the respondent." Standards 3.3.5(B).

Endnotes

1 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," *Human Rights Brief* 19, no. 2 (2012): 9.

2 American Bar Association Commission on Law and Aging and American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, 5–8, last modified March 25, 2005.

3 John Stuart Mill, *On Liberty*, 4th ed. (London: Longman, Roberts, & Green Co., 1869), 9.

4 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," *Human Rights Brief* 19, no. 2 (2012): 9.

5 Lawrence A. Frolik, "Guardianship Reform: When the Best is the Enemy of the Good," *Stanford Law and Policy Review* 9, no. 347 (Spring 1998): 347.

6 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," *Human Rights Brief* 19, no. 2 (2012): 8–9.

7 National Council on Disability, *The State of 21st Century Long-Term Services and Supports: Financing and Systems Reform for Americans with Disabilities*, December 2005, accessed January 24, 2018, www.ncd.gov/publications/2005/12152005.

8 National Guardianship Association, accessed January, 29, 2018, https://www.guardianship.org/what-is-guardianship/.

9 Unif. Guardianship, Conservatorship & Protective Arrangements Act § 102 (12) (Unif. Law Comm'n 2017), accessed January 24, 2018, http://www.uniformlaws.org/shared/docs/Guardianship%20and%20Protective%20Proceedings/2017AM_UGCOPPA_AsApproved.pdf.

10 *See* Va. Code Ann. § 64.2-2004.

11 *See* RULE 5.030.

12 American Bar Association Commission on Law and Aging, *State Adult Guardianship Legislation: Directions of Reforms – 2015*, accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2015_final_guardianship_legislative_update.authcheckdam.pdf.

13 *Mathews v. Eldridge*, 424 U.S. 348 (1976) ("The essence of due process is the requirement that "a person in jeopardy of serious loss (be given) notice of the case against him and opportunity to meet it.").

14 Nancy J. Knauer, "Defining Capacity: Balancing the Competing Interests of Autonomy and Need," *Temple Political & Civil Rights Law Review* 12 (Spring 2003): 325–327, 330.

15 *See* Conn. Gen. Stat. §§45a-655 (2017) (conservatorship); Conn. Gen. Stat. §§ 45a-656 (2017) (guardians of persons with intellectual disabilities); Minn. Stat. § 252A (2016) (appointment of guardian for an individual with a developmental disability); Minn. Stat. § 524.5-301 (2016) (appointment of a guardian for an incapacitated person).

16 *See* Wash. Rev. Code § 11.88.045(4) (2016).

17 *See* 755 Ill. Comp. Stat. 5/11a-10(a) (West 2017).

18 *See* Tex. Est. Code Ann. § 1101.103 (West 2017) (requiring that doctor's notes accompanying a petition for guardianship be dated no more than 120 days before the filing of the petition).

19 Naomi Karp and Erica Wood, "Guardianship Monitoring: A National Survey of Court Practices," *Stetson Law Review* 37 (Fall 2007): 163.

20 Unif. Guardianship and Protective Proceedings Act § 102 (Nat'l Conference of Comm'rs on Unif. State Laws 1997).
21 Mary Joy Quinn, *Guardianships of Adults: Achieving Justice, Autonomy, and Safety* (New York, NY: Springer Publishing, 2005), 35.
22 Ibid.
23 American Bar Association Commission on Law and Aging and American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, accessed January 24, 2018, 7, last modified March 25, 2005, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2012_aging_capacity_hbk_ch2.authcheckdam.pdf.
24 Ibid.
25 *See* Colo. Rev. Stat. Ann. § 15-14-311 (West 2017); Mont. Code Ann. § 72-5-316 (2015).
26 Salzman, *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 174; Teaster, et al., *Public Guardianship After 25 Years: In the Best Interest of Incapacitated People?*, 219; Frolik, *Promoting Judicial Acceptance and Use of Limited Guardianship*, 740–744.
27 *See* Mass. Gen. Laws ch. 190B, § 5A-102 (2017).
28 *See* 755 Ill. Comp. Stat. Ann. 5/11a-14(d) (2017).
29 Meta S. David, "Legal Guardianship of Individuals Incapacitated by Mental Illness: Where Do We Draw the Line?" *Suffolk University Law Review* 45 (2012): 479.
30 Unif. Guardianship and Protective Proceedings Act § 311 (Nat'l Conference of Comm'rs on Unif. State Laws 1997); Meta S. David, "Legal Guardianship of Individuals Incapacitated by Mental Illness: Where Do We Draw the Line?," *Suffolk University Law Review* 45 (2012): 479.
31 National Council on Disability, *Exhibit 1.1: Timeline of Major Legislative and Policy Initiatives Affecting People with Developmental Disabilities, 1960–2010*, table (February 15, 2011), accessed January 24, 2018, http://www.ncd.gov/rawmedia_repository/17c2ab41_51aa_4c6c_b069_300ee3d142c1.pdf.
32 20 U.S.C. §1400(c)(1) (2010).
33 Ellen Brantlinger, *Sterilization of People with Mental Disabilities: Issues, Perspectives, and Cases* (1995), 1–5.
34 Ibid., 4–5.
35 *Buck v. Bell*, 274 U.S. 200 (1927).
36 Mary Ziegler, "Reinventing Eugenics: Reproductive Choice and Law Reform After World War II," *Cardozo Journal of Law & Gender* 14 (Spring 2008): 322, Westlaw.
37 Stefan Kühl, *The Nazi Connection: Eugenics, American Racism, and German National Socialism* (New York, NY: Oxford University Press, 2001).
38 Robyn M. Powell, "Safeguarding the Rights of Parents with Intellectual Disabilities in Child Welfare Cases: The Convergence of Social Science and Law," *City University of New York Law Review* 20 (Winter 2016): 128, Westlaw (citing Eugenical Sterilization Act, Act of Mar. 20, 1924, ch. 394, 1924 Va. Acts 569 [repealed 1974]).
39 National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* (September 27, 2012), 44, accessed January 24, 2018, https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf.
40 National Council on Disability, *Rocking the Cradle*, page 16.
41 National Council on Disability, *Deinstitutionalization: Unfinished Business* (Companion Paper to Policy Toolkit), (September 2012), accessed January 24, 2018, https://www.ncd.gov/policy/deinstitutionalization-unfinished-business-companion-paper-policy-toolkit-0.
42 James W. Trent, Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States*, (Berkeley and Los Angeles: University of California Press, 1995), 31.
43 Robert Bogdan, Martin Elks, and James A. Knoll, *Picturing Disability: Beggar, Freak, Citizen and Other Photographic Rhetoric* (Syracuse: Syracuse University Press, 2012), 69, 71.

44 Staff, "Excerpts from Statement by Kennedy," *The New York Times*, September 10, 1965, quoted in National Council on Disability, *Forty Years After The Willowbrook Consent Decree, NCD Celebrates How Far We've Come*, May 4, 2015, accessed January 24, 2018, https://ncd.gov/newsroom/05042015#_edn3.

45 Geraldo Rivera, "Exposé of Willowbrook State School," WABC-TV, January 6, 1972, accessed June 27, 2017, http://dlib.nyu.edu/undercover/expose-willowbrook-state-school-geraldo-rivera-wabc-tv; Bill Baldini, "Suffer the Little Children," NBC10 Philadelphia, 1968, accessed January 24, 2018, http://www.preservepennhurst.com/default.aspx?pg=26.

46 Ibid.

47 Bill Baldini, "Suffer the Little Children," NBC10 Philadelphia, 1968, accessed January 24, 2018, http://www.preservepennhurst.com/default.aspx?pg=26.

48 James W. Trent, Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States*, (Berkeley and Los Angeles: University of California Press, 1995), 1.

49 Phillip M. Massad and Bruce Dennis Sales, "Guardianship: An Acceptable Alternative to Institutionalization?," *American Behavioral Scientist* 24, no. 6 (1981): 756.

50 *Bull Am Acad Psychiatry Law* 15, no. 1 (1987): 77.

51 Iowa Department of Human Services, *Money Follows the Person Guardian Consent to Participate in Transition Planning*, accessed January 24, 2018, http://dhs.iowa.gov/sites/default/files/470-4564-Guardian%20Consent.pdf.

52 Kristin Baker, et al., *Money Follows the Person Rebalancing Demonstration: Closed Cases Report for 2014*, UCONN Center on Aging, accessed January 24, 2018, https://health.uconn.edu/dev-aging/wp-content/uploads/sites/102/2017/03/2014_closed_cases_report.pdf.

53 University of California at Berkeley Disabled Students' Program, *About*, accessed January 24, 2018, http://dsp.berkeley.edu/about.

54 Wendy Edelstein, "Ed Roberts, disability-rights leader and Cal alum, gets his own state day," *Berkeley News*, July 27, 2010, accessed January 24, 2018, http://news.berkeley.edu/2010/07/27/roberts/.

55 Access Living, *Independent Living History: A Brief History of the Independent Living Movement*, accessed January 24, 2018, https://www.accessliving.org/Independent-Living-History.

56 Jacobus Tenbroek, "The Right to Live in the World: The Disabled in the Law of Torts," *California Law Review* 54, no. 2 (1966): 918.

57 Rehabilitation Act of 1973, 29 U.S. § 794(a) (1973).

58 Rehabilitation Act of 1973, P.L. 93-112, 87 Stat. 355.

59 Kitty Cone, "Short History of the 504 Sit-In," *Disability Rights and Education Defense Fund*, accessed January 24, 2018, https://dredf.org/504-sit-in-20th-anniversary/short-history-of-the-504-sit-in/.

60 National Council on Disability, *Rehabilitating Section 504*, Feb. 12, 2003, accessed January 24, 2018, 13, https://ncd.gov/rawmedia_repository/77de6d4a_3c88_46e9_aed4_bcea96a3ac4d.pdf.

61 National Council on Disability, *Rising Expectations: The Developmental Disabilities Act Revisited*, Feb. 14, 2011, accessed January 24, 2018, https://ncd.gov/publications/2011/Feb142011#toc6.

62 Developmental Disabilities Assistance and Bill of Rights Act of 1975, P.L. 94-103, 89 Stat. 486 (1975).

63 Education for All Handicapped Children Act, P.L. 94-142, 89 Stat. 773 (1975); Individuals with Disabilities Education Act, 20 U.S.C. 20 §1400 (1990).

64 Ibid.

65 Donna Langston, "Black Civil Rights, Feminism, and Power," *Race, Gender & Class* 5, no. 2 (1998): 158.

66 Nancy J. Knauer, "Symposium: Lawyering for the Mentally Ill: Defining Capacity: Balancing the Competing Interests of Autonomy and Need," *Temple Political and Civil Rights Law Review* 12 (2003): 321.

67 Ibid., 341–342.

68 *O'Connor v. Donaldson*, 422 U.S. 575 (1975).

69 *Wyatt v. Stickney*, 325 F. Supp. 781 (M.D. Ala. 1971); National Council on Disability, *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community*, accessed January 24, 2018, 11, https://ncd.gov/rawmedia_repository/HCBS%20Report_FINAL.pdf.
70 Samuel R. Bagenstos, "The Past and Future of Deinstitutionalization Litigation," *Cardozo Law Review* 34, no. 1 (2012): 25.
71 K. Charlie Lakin, Robert Prouty, and Kathryn Coucouvanis, "Twenty-Year Retrospective on Proposals to Eliminate the 'Institutional Bias' in Medicaid for Persons with ID/DD," *Mental Retardation* 44, no. 6 (2006): 450–454.
72 42 U.S. Code § 1396a.
73 Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, 95 Stat. 357, § 2176 (1981).
74 National Council on Disability, *Consumer-Directed Health Care: How Well Does It Work?*, Oct. 26, 2004, accessed January 24, 2018, 24, http://www.ncd.gov/rawmedia_repository/7fc3e5bf_73f5_4d9b_a97e_90d19558ad74.pdf.
75 42 U.S.C. 1396(n).
76 National Council on the Handicapped, *Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities – with Legislative Recommendations* (Washington, DC: U.S. Government Printing Office, 1986), 18, accessed January 24, 2018, http://www.ncd.gov/publications/1986/February1986.
77 Ibid.
78 National Council on Disability, National Council on Disability: 20 Years of Independence, July 26, 2004, accessed January 24, 2018, 15, https://ncd.gov/rawmedia_repository/738f18be_d833_4546_998b_af343a6cb24c.pdf.
79 Americans with Disabilities Act of 1990, P.L. 101-336, 104 Stat. 327 (1990).
80 *Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581 (1999).
81 *Brown v. Board of Education*, 349 U.S. 294 (1955); Mary C. Cerreto, "Olmstead: The *Brown v. Board of Education* for Disability Rights Promises, Limits, and Issues," *Loyola Journal of Public Interest Law* 3, no. 47 (2001).
82 Olmstead, 527 U.S. at 581-82.
83 Ibid., 581-82, 607.
84 Ibid., 587.
85 Ibid., 597.
86 Ibid., 599, 609.
87 Leslie Salzman, "Rethinking Guardianship (Again): Substituted Decision Making As A Violation Of The Integration Mandate Of Title II Of The Americans With Disabilities Act," *University of Colorado Law Review* 81 (2010): 157.
88 Division for Social Policy and Development Disability, *Convention on the Rights of Persons with Disabilities (CRPD)*, United Nations, accessed January 24, 2018, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
89 U.S. International Council on Disability, *The Convention on the Rights of Persons with Disabilities*, accessed January 24, 2018, http://usicd.org/index.cfm/crpd.
90 United Nations, Division for Social Policy and Development Disability, Convention on the Rights of Persons with Disabilities (CRPD), accessed March 3, 2018, https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.
91 Ibid.
92 National Council on Disability, *Statement on the Convention on the Rights of Persons with Disabilities (CRPD)*, July 14, 2014, accessed June 27, 2017, https://www.ncd.gov/publications/2014/07142014
93 Sally B. Hurme and Erica Wood, "Guardianship Accountability Then and Now: Tracing Tenets for an Active Court Role," *Stetson Law Review* 31 (2002): 867.

94 A. Frank Johns and Vicki Joiner Bowers, "Guardianship Folly: The Misgovernment of Parens Patriae and the Forecast of its Crumbling Linkage to Unprotected Older Americans in the Twenty-First Century—A March of Folly? Or Just a Mask of Virtual Reality?," *Stetson Law Review* 27 (1997): 17–20.
95 A. Frank Johns, "Ten Years After: Where is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?," *Elder Law Journal* 7 (1999): 48.
96 Jennifer L. Wright, "Protecting Who From What, And Why, And How? A Proposal for an Integrative Approach to Adult Protective Proceedings," *Elder Law Journal* 12 (2004): 57.
97 Black's Law Dictionary, 10th edition, s. v. "Parens Patriae."
98 U.S. Const. amend. X.
99 U.S. Const. art. VI, cl. 2.
100 Neil B. Posner, "The End of Parens Patriae in New York: Guardianship Under the New Mental Health Hygiene Law Article 81," *Marquette Law Review* 79 (1996): 606.
101 Kristin B. Glen, "Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond," *Columbia Human Rights Law Review* 44 (2012): 128.
102 *O'Connor v. Donaldson*, 422 U.S. 563, 576 (1975).
103 A. Frank Johns, "Ten Years After: Where is the Constitutional Crisis with Procedural Safeguards and Due Process in Guardianship Adjudication?," *Elder Law Journal* 7 (1999): 57.
104 *Youngberg v. Romeo*, 457 U.S. 307, 319 (1982).
105 Michael L. Perlin, Pamela R. Champine, Henry A. Dlugacz, and Mary A. Connell, *Competence in the Law: From Legal Theory to Clinical Application* (Hoboken, NJ: John Wiley & Sons, 2008), 248.
106 Fred Bayles and Scott McCartney, "Guardians of the Elderly: An Ailing System Part 1:Declared 'Legally Dead' by a Troubled System," *Associated Press*, September 19, 1987, accessed January 24, 2018, http://www.apnewsarchive.com/1987/Guardians-of-the-Elderly-An-Ailing-System-Part-I-Declared-Legally%20Dead-by-a-Troubled-System/id-1198f64bb05d9c1ec690035983c02f9f.
107 U.S. Congress, 1987, Abuses in Guardianship of the Elderly and Infirm: A National Disgrace: Hearings Before the Subcommittee on Health and Long-Term Care of the Select Committee on Aging, 100th cong., 1st sess., 5-10, 8 (statement of Claude Pepper), accessed January 24, 2018, http://files.eric.ed.gov/fulltext/ED297241.pdf.
108 National Guardianship Association, *About NGA: Mission, Overview and History*, accessed November 10, 2016, https://www.guardianship.org/about-us/who-we-are/.
109 Sally Balch Hurme and Erica Wood, "Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role," *Stetson Law Review* 31 (2002): 869.
110 ABA Commission on the Mentally Disabled and ABA Commission on Legislative Problems of the Elderly, *Guardianship: An Agenda for Reform—Recommendations of the National Guardianship Symposium and Policy of the American Bar Association*, accessed January 17, 2017, https://www.americanbar.org/content/dam/aba/administrative/law_aging/2011/2011_aging_gship_agda_refrm.authcheckdam.pdf.
111 Sally Balch Hurme, & Erica Wood, "Guardian Accountability Then and Now: Tracing Tenets for an Active Court Role," *Stetson Law Review* 31 (2002): 870.
112 Ibid., 869–870.
113 Ibid., 870.
114 David English, "Amending the Uniform Guardianship and Protective Proceedings Act to Implement the Standards and Recommendations of the Third National Guardianship Summit," *National Academy of Elder Law Attorneys Journal* 12, no. 33 (2016): 34–40.
115 Nina A. Kohn and Catheryn Koss, "Lawyers for Legal Ghosts: The Legality and Ethics of Representing Persons Subject to Guardianship," *Washington Law Review* 91 (2016): 606.
116 Sally Hurme and Erica Wood, "Introduction," *Utah Law Review,* no. 3 (2012): 1160.
117 A. Frank Johns and Charles P. Sabatino, "Wingspan—The Second National Guardianship Conference, Recommendations," *Stetson Law Review* 31, no. 3 (Spring 2002): 595–609, HeinOnline.
118 Ibid.

119 David English, "Amending the Uniform Guardianship and Protective Proceedings Act to Implement the Standards and Recommendations of the Third National Guardianship Summit," *National Academy of Elder Law Attorneys Journal* 12, no. 33 (2016): 36.
120 Ibid.
121 A. Frank Johns and Charles P. Sabatino, "Wingspan—The Second National Guardianship Conference, Introduction," *Stetson Law Review* 31, no. 3 (Spring 2002): 593, HeinOnline.
122 Leslie P. Francis, "Preface Third National Guardianship Summit: Standards of Excellence," *Utah Law Review,* no. 3 (2012): 1157.
123 American Bar Association Commission on Law and Aging, *About the ACL Grant*, accessed January 24, 2018, https://www.americanbar.org/groups/law_aging/resources/wings-court-stakeholder-partnerships/about-the-grant.html.
124 Ibid.
125 United Nations Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.C. 3., art. 12.
126 Alex L. Pearl, *Article 12 of the United Nations Convention on the Rights of Persons with Disabilities and the Legal Capacity of Disabled People: The Way Forward?*, accessed January 24, 2018, http://1neaqn120jll48xd411i5uav.wpengine.netdna-cdn.com/files/2013/09/Article-12_Pearl.pdf.
127 Robert D. 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," *Human Rights Brief* 19 (2012): 3.
128 Ibid., 8–9.
129 Robert Dinerstein, Esme Grant Grewal, and Jonathan Martinis, "Emerging International Trends and Practices in Guardianship Law for People with Disabilities," *ILSA Journal of International and Comparative Law* 22, no. 2 (Winter 2016): 443, n.38.
130 Leslie Salzman, "Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," *University of Colorado Law Review* 81 (2010): 157.
131 Uniform Law Commission, *Guardianship, Conservatorship, and Other Protective Arrangements Act Committee*, accessed January 24, 2018, http://www.uniformlaws.org/Committee.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act.
132 David English, "Amending the Uniform Guardianship and Protective Proceedings Act to Implement the Standards and Recommendations of the Third National Guardianship Summit," *National Academy of Elder Law Attorneys Journal* 12, no. 33 (2016): 33–55.
133 Unif. Guardianship and Protective Proceedings Act Prefatory Note (Nat'l Conference of Comm'rs on Unif. State Laws 2017).
134 Cathy Free and Nicole Weisensee Egan, "Woman with Down Syndrome Fights for Her Freedom - and Wins," *People Magazine*, March 7, 2014, accessed January 24, 2018, http://people.com/human-interest/woman-with-down-syndrome-fights-for-her-freedom-and-wins/; Theresa Vargas, "Virginia Woman with Down Syndrome Becomes Hero to the Disabled," *Washington Post*, August 17, 2013, accessed January 24, 2018, https://www.washingtonpost.com/local/virginia-woman-with-down-syndrome-becomes-hero-to-the-disabled/2013/08/17/0da21766-062e-11e3-a07f-49ddc7417125_story.html?utm_term=.f39da4150d5d; Don Dahler, "Woman with Down Syndrome Becomes Icon for Disabled," *CBS News*, November 30, 2013, accessed January 24, 2018, http://www.cbsnews.com/news/woman-with-down-syndrome-becomes-icon-for-disabled/.
135 Jenny Hatch, "My Story," *Inclusion* 3, no. 1 (2015): 34.
136 *Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 2, 2013); Jenny Hatch, Samantha A. Crane, and Jonathan G. Martinis, "Unjustified Isolation Is Discrimination: The Olmstead Case Against Overbroad and Undue Organizational and Public Guardianship," *Inclusion* 3, no. 2 (2015): 66.

137 Andy Fox, "Special Report: Justice for Jenny," *WAVY*, November 3, 2016, accessed January 24, 2018, http://wavy.com/2016/11/03/special-report-justice-for-jenny/.
138 Jasmine E. Harris, "Processing Disability," *American University Law Review* 64 (2015): 514.
139 Human Services Research Institute, *Supported Decision Making: A Collaborative Approach—Pilot Evaluation Year 1 Report*, accessed January 24, 2018, http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf.
140 University of Texas School of Law, *Texas Law INCLUDE Project*, accessed January 24, 2018, https://law.utexas.edu/probono/opportunities/texas-law-include-project/.
141 New York State Developmental Disabilities Planning Council, *Supported Decision Making*, accessed January 24, 2018, https://ddpc.ny.gov/supported-decision-making-0.
142 Tex. Estates Code § 1002.0015.
143 Sally Hurme and Erica Wood, "Introduction," *Utah Law Review*, no. 3 (2012): 1162.
144 U.S. Congress, 2017, Examining the Social Security Administration's Representative Payee Program: Who Provides Help?: Hearings Before the Committee on Ways and Means, Subcommittees on Oversight and Social Security, 115th cong., 1st sess., (statement of Brenda K. Uekert), accessed J January 24, 2018, https://waysandmeans.house.gov/wp-content/uploads/2017/03/20170322SS-Testimony-Uekert.pdf.
145 Brenda K. Uekert and Richard Van Duizend, "Adult Guardianships: A 'Best Guess' National Estimate and the Momentum of Reform," *National Center for State Courts* (2011): 108, accessed January 24, 2018, http://ncsc.contentdm.oclc.org/cdm/ref/collection/ctadmin/id/1846.
146 Center for Elders and the Courts, Adult Guardianship Court Data and Issues Results from an Online Survey, 14, March 2, 2010, accessed June 30, 2017, http://aja.ncsc.dni.us/pdfs/GuardianshipSurveyReport_FINAL.pdf
147 Naomi Karp and Erica Wood, *Choosing Home for Someone Else: Guardian Decisions on Long-Term Services and Supports*, 1, August 2013, accessed January 24, 2018, http://www.aarp.org/content/dam/aarp/research/public_policy_institute/cons_prot/2013/guardian-decisions-on-ltss-report-AARP-ppi-cons-prot.pdf.
148 United States Government Accountability Office, *Better Information Needed on Nursing Assistants, Home Health Aides, and Other Direct Care Workers*, 1, August 2016, accessed January 24, 2018, https://www.gao.gov/assets/680/679100.pdf.
149 Court Statistics Project, Caseload Highlights, the Need for Improved Guardianship Data. Accessed January 25, 2018, http://www.courtstatistics.org/~/media/Microsites/Files/CSP/Highlights/15_2_Adult_Guardianship_Data.ashx.
150 Administrative Conference of the United States, *SSA Representative Payee: Survey of State Guardianship Laws and Court Practices*, 5, December 24, 2014, accessed January 24, 2018, https://www.acus.gov/sites/default/files/documents/SSA%2520Rep%2520Payee_State%2520Laws%2520and%2520Court%2520Practices_FINAL.pdf.
151 Center for Elders and the Courts, Adult Guardianship Court Data and Issues Results from an Online Survey, 14, March 2, 2010, accessed June 30, 2017, http://aja.ncsc.dni.us/pdfs/GuardianshipSurveyReport_FINAL.pdf
152 Ibid., 5.
153 Jean Callahan, Raquel Malina Romanick, and Angela Ghesquiere, "Guardianship Proceedings in New York State: Findings and Recommendations," *Bifocal* 37, no. 4. (March/April 2016): 85, accessed January 24, 2018, https://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALMar-Apr2016.authcheckdam.pdf.
154 Texas Office of Court Administration, *Texas Guardianship Cases: Improving Court Processes and Monitoring Practices in Texas Courts*, 3, accessed January 24, 2018, http://www.txcourts.gov/media/1073478/guardianship-study-20150303.pdf.
155 Indiana Adult Guardianship State Task Force, *Who's Overseeing the Overseers? A Report on the State of Adult Guardianship in Indiana*, 1, February 2012, accessed January 24, 2018, https://www.in.gov/judiciary/admin/files/ad-guard-2012-full-report.pdf.
156 Nevada Courts, "Conservatorship Accountability Project (CAP) Aims to Improve Nevada's Guardianship Courts," January 22, 2016, accessed January 24, 2018, http://nvcourts.gov/Supreme/News/Conservatorship_Accountability_Project_(CAP)_Aims_to__Improve_Nevada%E2%80%99s_Guardianship_Courts/.

157 United States Government Accountability Office, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults*, November 2016, accessed January 24, 2018, https://www.gao.gov/assets/690/681088.pdf.
158 United States Government Accountability Office, *Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors*, September 2010, accessed January 24, 2018, https://www.gao.gov/assets/320/310741.pdf.
159 Ibid at 7.
160 Elder Abuse Prevention and Prosecution Act, 115 P.L. 70 (2017).
161 Patrick Michels, *Who Guards the Guardians?*, accessed January 24, 2018, https://www.texasobserver.org/texas-guardianship-abuse/.
162 Colton Lochhead, "Grand Jury Indicts Nevada Guardian on More Than 200 Charges," *Las Vegas Review-Journal*, accessed January 24, 2018, https://www.reviewjournal.com/crime/grand-jury-indicts-nevada-guardian-on-more-than-200-charges/.
163 Rachel Aviv, "How the Elderly Lose Their Rights," *The New Yorker*, accessed January 24, 2018, https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights.
164 Uekert et. al., "Conservator Exploitation Summary Research Reports," National Center for State Courts, National Forum on Financial Exploitation by Conservators Working Paper (Draft), page 20.
165 Mark B. Heffner, "From Idiots and Lunatics to Incapacitated Persons and Respondents," *Roger Williams Law Review* 21 (Summer 2016): 554.
166 Ibid.
167 Scott J. Shackelford and Lawrence M. Friedman, "Legally Incompetent: A Research Note," *American Journal of Legal History* 49 (2007): 321.
168 Nancy J. Knauer, "Defining Capacity: Balancing the Competing Interests of Autonomy and Need," *Temple Political and Civil Rights Law Review* 12 (Spring 2003): 325.
169 American Bar Association Commission on Law and Aging and American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, 7, accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2012_aging_capacity_hbk_ch2.authcheckdam.pdf.
170 Margaret Isabel Hall, "Mental Capacity in the (Civil) Law: Capacity, Autonomy, and Vulnerability," *McGill Law Review* 58, no. 1 (2012): 64.
171 Ibid., 61.
172 Joel Feinberg, *The Moral Limits of Criminal Law Volume 3: Harm to Self* (Oxford: Oxford University Press, 1986), 54.
173 Thomas Jefferson, *Original draft of the Declaration of Independence*, 1776.
174 A.P. Herbert, *Misleading Cases in the Common Law* (London: Methuen, 1927).
175 John Stuart Mill, *Essays on Some Unsettled Questions of Political Economy* (London: Longmans, Green, Reader, and Dyer, 1874).
176 Ibid; Alain Samson, *An Introduction to Behavioral Economics*, accessed January 24, 2018, https://www.behavioraleconomics.com/introduction-to-be/.
177 Binyamin Appelbaum, "Nobel in Economics Is Awarded to Richard Thaler," *The New York Times*, accessed January 24, 2018, https://www.nytimes.com/2017/10/09/business/nobel-economics-richard-thaler.html?_r=0.
178 Ohio Rev. Code Ann. § 2111.02 (West 2017); Colo. Rev. Stat. § 15-14-311 (West 2017h).
179 American Bar Association Commission on Law and Aging, *Representation and Investigation in Guardianship Proceedings*, accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/law_aging/chartrepresentationandinvestigation.authcheckdam.pdf.
180 *Shen v. Parkes*, 100 So. 3d 1189 * (Fla. Dist. Ct. 2012).
181 Md. R Guard and Fiduciaries Rule 10-202 (2016).
182 *Daubert v. Merrell Dow Pharm., Inc.*, 509 U.S. 579, 589 (1993).

183 Lawrence A. Frolik, "Science, Common Sense, and the Determination of Mental Capacity," 5 Psych. Pub. Pol. and L. 41, 56.
184 Lawrence J. Markson, et al., "Physician Assessment of Patient Competence," *Journal of the American Geriatrics Society* 42 (1994): 1076–1078.
185 Lawrence A. Frolik, "Promoting Judicial Acceptance and Use of Limited Guardianship," *Stetson Law Review* 31 (2002): 741; A. Frank Johns, "Person-Centered Planning in Guardianship: A Little Hope for the Future," *Utah Law Review,* no. 3 (2012); Jalayne Arias, "A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity," *American Journal of Law and Medicine* 39 (2013): 148.
186 Fla. Stat. § 744.331 (2017). Ky. Rev. Stat. Ann. § 387.540 (West 2016).
187 Md. R Guard and Fiduciaries Rule 10-202 (2016).
188 Ala. Code § 26-2A-102 (2017); Idaho Code § 15-5-303 (2017); Mich. Comp. Laws § 330.1612 (2017).
189 Colo. Rev. Stat. § 15-14-306 (2017).
190 Lawrence A. Frolik, "Science, Common Sense, and the Determination of Mental Capacity," *Psychology, Public Policy, and Law* 5 (1999): 42.
191 Ben A. Rich, "Medical Paternalism v. Respect for Patient Autonomy: The More Things Change the More They Stay the Same," *Michigan State University Journal of Medicine and Law* 10 (2006): 98.
192 Jalayne J. Arias, "A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity," *American Journal of Law and Medicine* 39 (2013): 134.
193 Latha Velayudhan, et al., "Review of Brief Cognitive Tests for Patients with Suspected Dementia," *International Psychogeriatrics* 26, no. 8: 1247–1262, doi: 10.1017/S1041610214000416.
194 Lawrence A. Frolik and Alison M. Barns, *Elder Law: Cases and Materials,* 6th ed. (New Providence, NJ: LexisNexis, 2015).
195 Ibid.
196 Marshall B. Kapp and Douglas Mossman, "Measuring Decisional Capacity: Cautions on the Construction of a 'Capacimeter,'" *Psychology, Public Policy, and Law* 2 (1996): 73.
197 Robert P. Roca, "Determining Decisional Capacity: A Medical Perspective," *Fordham Law Review* 62 (1994): 1182–1183.
198 Angela Juby, Shirly Tench, and Victoria Baker, "The Value of Clock Drawing in Identifying Executive Cognitive Dysfunction in People with a Normal Mini-Mental State Examination Score," *Canadian Medical Association Journal* 167, no.8 (2002): 859–864.
199 Marshall B. Kapp and Douglas Mossman, "Measuring Decisional Capacity: Cautions on the Construction of a 'Capacimeter,'" *Psychology, Public Policy, and Law* 2 (1996): 73.
200 American Psychological Association, *ABA/APA Assessment of Capacity in Older Adults*, accessed January 24, 2018, http://www.apa.org/pi/aging/programs/assessment/index.aspx.
201 Jennifer Moye and Aanand Naik, "Preserving Rights for Individuals Facing Guardianship," *Journal of the American Medical Association* 305, no. 9 (2011): 937.
202 Ibid.
203 American Bar Association Commission on Law and Aging and American Psychological Association, *Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers*, 7, accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/law_aging/2012_aging_capacity_hbk_ch2.authcheckdam.pdf.
204 Dorothy Millar, "Addition to Transition Assessment Resources: A Template for Determining the Use of Guardianship Alternatives for Students who have Intellectual Disability," *Education and Training in Autism and Developmental Disabilities* 49, no. 2 (2014): 171–188.
205 Jenica Cassidy, "Restoration of Rights in the Termination of Adult Guardianship," *Elder Law Journal* 23, no. 1 (2015): 103.
206 Glenna Goldis, "When Family Courts Shun Adversarialism," *University of California at Davis Journal of Juvenile Law and Policy* 18 (Summer 2014): 198.

207 Lawrence A. Frolik, "Promoting Judicial Acceptance and Use of Limited Guardianship," *Stetson Law Review* 31 (Spring 2002): 735.
208 Israel Doron and Ann M. Soden, *Beyond Elder Law: New Directions in Law and Aging* (2012).
209 CRPD Article 12.
210 Charles P. Sabatino and Erica Wood, "The Conceptualization of Capacity of Older Persons in Western Law," in *Beyond Elder Law: New Directions in Law and Aging,* 35, 36 (Israel Doron & Ann Snoden eds., 2012).
211 Lauren B. Lisi, Anne Burns, and Kathleen Lussenden, *National Study of Guardianship Systems: Findings and Recommendations* (Ann Arbor, MI: Center for Social Gerontology, 1994).
212 Utah State Courts Ad Hoc Committee on Probate Law and Procedure, *Final Report to the Judicial Council*, preface, February 23, 2009, accessed January 24, 2018, https://www.utcourts.gov/committees/adhocprobate/Guardian.Conservator.Report.pdf.
213 Elaine Jaryik and Lois M. Collins, "Gray Area: Who Should Make Choices for the Elderly?" *Deseret News* (Salt Lake City, UT), November 24, 2008, accessed January 24, 2018, http://www.deseretnews.com/article/705265008/Who-should-make-choices-for-the-elderly.html?pg=all.
214 Utah State Courts Ad Hoc Committee on Probate Law and Procedure, *Final Report to the Judicial Council*, 4, February 23, 2009, accessed January 24, 2018, https://www.utcourts.gov/committees/adhocprobate/Guardian.Conservator.Report.pdf.
215 *See* University Legal Services, *Time for Change: A Call to Reform the District of Columbia's Guardianship System*, March 10, 2014, accessed January 24, 2018, http://www.uls-dc.org/Time%20for%20Change.pdf (finding the DC legal system provides no safeguards for ensuring alternatives to guardianship are explored prior to appointment; the court rarely assigns guardians with limited powers; there is no proscribed format for clinical assessments; people alleged to be incapacitated are rarely granted meaningful participation in the judicial proceedings; the quality of legal representation is pre and post appointment proceedings is poor, attorneys regularly represent best interests rather than expressed interests of their clients).
216 Kenneth C. Dudley and R. Turner Goins, "Guardianship Capacity Evaluations of Older Adults: Comparing Current Practice to Legal Standards in Two States," *Journal of Aging and Social Policy* 15, no. 1 (2003): 97–115, doi: 10.1300/J031v15n01_06; Jennifer Moye, et al., "Clinical Evidence in Guardianship of Older Adults is Inadequate: Findings from a Tri-State Study," *Gerontologist* 47 (2007): 604–612. doi: 10.1093/geron/47.5.604; Moye and Naik, "Preserving Rights for Individuals Facing Guardianship," 936.
217 Salzman, "Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," 175–177; Arias, "A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity," 158–159.
218 Dennis Romboy, "ACLU Sues Utah over Disabled People's Right to a Layer in Guardianship Cases," *Deseret News*, accessed January 24, 2018, http://www.deseretnews.com/article/865684409/ACLU-sues-Utah-over-disabled-peoples-right-to-a-lawyer-in-guardianship-cases.html.
219 Brenda K. Uekert and Richard Van Duizend, *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform*, in National Center for State Courts, *Future Trends in State Courts 2011: A Special Focus on Access to Justice*, 109 (2011).
220 American Bar Association Commission on Law and Aging, *Representation and Investigation in Guardianship Proceedings*, chart (2015), accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/law_aging/chartrepresentationandinvestigation.authcheckdam.pdf.
221 Salzman, "Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," 174; Teaster, et al., "Public Guardianship After 25 Years: In the Best Interest of Incapacitated People?," 219; Frolik, "Promoting Judicial Acceptance and Use of Limited Guardianship," 740–744.
222 Salzman, "New Perspectives on Guardians and Mental Illness: Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?," 305.
223 Frolik, "Promoting Judicial Acceptance and Use of Limited Guardianship," 735–755.

224 Salzman, "Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," 174–175; Frolik, "Guardianship Reform: When the Best Is the Enemy of the Good," 352–353.

225 National Council on Disability, *Rising Expectations: The Developmental Disabilities Act Revisited*, Feb. 14, 2011, accessed January 24, 2018, https://ncd.gov/publications/2011/Feb142011#toc6.

226 Karen Andreasian, et. al., "Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities," *CUNY Law Review,* no. 18 (2015): 287, 288.

227 Ibid.

228 F.S. 393.12.

229 National Resource Center for Supported Decision-Making, *Ryan King - Updated*, accessed January 24, 2018, http://supporteddecisionmaking.org/impact-stories/ryan-king-updated. Quality Trust for Individuals with Disabilities, The Burton Blatt Institute, and The National Resource Center for Supported Decision-Making, Press Release: Freedom for Ryan King, accessed March 3, 2018, http://www.supporteddecisionmaking.org/node/427.

230 C. E. Rood, A. Kanter, and J. Causton, "Presumption of incompetence: The systematic assignment of guardianship within the transition process," *Research and Practice for Persons with Severe Disabilities 39,* no. 4 (2014): 319–328.

231 Dorothy Squatrito Millar, "Age of Majority, Transfer of Rights and Guardianship: Considerations for Families and Educators," *Education and Training in Developmental Disabilities* 38, no. 4, Special Conference Issue Research to Practice (December 2003): 378–397.

232 Karen Andreasian, et. al., "Revisiting S.C.P.A. 17-A: Guardianship for People with Intellectual and Developmental Disabilities," *CUNY Law Review,* no. 18 (2015): 287, 319.

233 Matt Jameson, et al., "Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities," *Research and Practice for Persons with Severe Disabilities* 40, no. 1 (March 1, 2015): 36–51.

234 Workforce Investment Opportunity Act, P.L. 113-128, 128 Stat 1425 (2014).

235 Office of the State Superintendent of Education, *Education Decision-Making & Transfer of Rights*, accessed January 24, 2018, https://osse.dc.gov/service/education-decision-making.

236 National Resource Center for Supported Decision Making, *Understanding My IEP*, accessed January 24, 2018, http://supporteddecisionmaking.org/legal-resource/understanding-my-iep.

237 Family Voices of Wisconsin, *Assisted Decision Making: What Parents of Transition Age Youth Need to Know*, accessed January 24, 2018, http://www.familyvoicesofwisconsin.com/wp-content/uploads/2015/04/Assisted-Decision-Making-Fact-Sheet-New.pdf.

238 Florida Developmental Disabilities Council, Inc., *Legal and Reference Resources*, accessed January 24, 2018, http://www.fddc.org/node/2890.

239 FSGA Legislative Committee, *White Paper on Guardian Compensation*, accessed January 24, 2018, http://www.guardianassociation.org/Resources/Documents/White%20Paper%20on%20Guardian%20Compensation%207%2022%2013.pdf.

240 Pamela B. Teaster, Erica F. Wood, Winsor C. Schmidt, Jr. and Susan A. Lawrence, *Public Guardianship After 25 Years: In The Best Interests Of Incapacitated People*, 94 (A.B.A. 2007).

241 Ibid., 98.

242 FSGA Legislative Committee, *White Paper on Guardian Compensation*, accessed January 24, 2018, http://www.guardianassociation.org/Resources/Documents/White%20Paper%20on%20Guardian%20Compensation%207%2022%2013.pdf.

243 Symposium: Third National Guardianship Summit: Standards of Excellence: Standards for Guardian Fees, 2012 Utah L. Rev. 1575, 1583, accessed January 24, 2018, https://advance.lexis.com/api/document/collection/analytical-materials/id/57KH-JXP0-00CW-50B2-00000-00?page=1583&reporter=8440&cite=2012%20Utah%20L.%20Rev.%201575&context=1000516.

244 Fla. Stat. § 744.2001. (2017).

245 Elder Abuse Prevention and Prosecution Act, 115 P.L. 70 (2017).

246 Mary Joy Quinn, *Guardianships of Adults: Achieving Justice, Autonomy, and Safety* (New York, NY: Springer Publishing. Co., 2005), 17.
247 Michael L. Perlin, et al., *Competence in the Law: From Legal Theory to Clinical Application* (Hoboken, NJ: John Wiley & Sons, 2008), 246.
248 Roger J. Stancliffe, et al., "Substitute decision-making and personal control: Implications for self-determination," *Mental Retardation* 38, no. 5 (October 1, 2000): 407.
249 Kristin Booth Glen, Supported Decision-Making and the Human Right of Legal Capacity, *Inclusion* 3, no. 1 (March 2015):1, 3–4.
250 A. Frank Johns, "Person-Centered Planning in Guardianship: A Little Hope for the Future," *Utah Law Review*, no. 3 (2012): 1543.
251 Ibid.
252 Leslie Salzman, "Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?," *Saint Louis University Journal of Health Law & Policy* 4 (2011): 289–293.
253 Edward L. Deci, *Intrinsic Motivation* (Plenum Publishing, 1975), 208; B.J. Winick, "The Side-Effects of Incompetency Labeling and the Implications for Mental-Health Law," *Psychology Public Policy and Law* 1 (1995): 21; Jennifer L. Wright, "Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA," *International Journal of Law & Psychiatry* 33 (2010): 354.
254 Leslie Salzman, "Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?," *Saint Louis University Journal of Health Law & Policy* 4 (2011): 283.
255 United States Government Accountability Office, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults*, 6, November 2016, accessed January 24, 2018, https://www.gao.gov/assets/690/681088.pdf; United States Government Accountability Office, *Guardianships: Cases of Financial Exploitation, Neglect, and Abuse of Seniors*, September 2010, accessed January 24, 2018, https://www.gao.gov/assets/320/310741.pdf.
256 Ibid., 7.
257 Ibid., 9.
258 United States Government Accountability Office, *Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults*, 12–14, November 2016, accessed January 24, 2018, https://www.gao.gov/assets/690/681088.pdf.
259 U.S. Congress, 2016, Trust Betrayed: Financial Abuse of Older Americans by Guardians and Others in Power Hearing before the Senate Special Committee on Aging, 115th cong, accessed January 29, 2018, https://www.aging.senate.gov/hearings/trust-betrayed_financial-abuse-of-older-americans-by-guardians-and-others-in-power.
260 National Council on Disability, *Experience of Voters with Disabilities in the 2012 Election Cycle*, 81, October 24, 2013, accessed January 24, 2018, https://ncd.gov/rawmedia_repository/8%2028%20HAVA%20Formatted%20KJ%20V5%20508.pdf.
261 Rabia S. Belt, *Mental Disability and the Right to Vote* (Ph.D. diss., University of Michigan, 2015): 4.
262 Associated Press, "Restored Voting Rights Sought for Disabled People," *CBS News*, August 23, 2016, accessed January 24, 2018, http://www.cbsnews.com/news/restored-voting-rights-sought-for-disabled-people/.
263 Caroline Modarressy-Tehrani, "One Disabled Man's Fight to Restore His Right to Vote," *Vice News* video, 4:51, October 30, 2016, accessed January 24, 2018, https://news.vice.com/story/disability-activist-voting-rights.
264 Bazelon Center for Mental Health Law, *It's Your Right: A Guide to the Voting Rights of People with Mental Disabilities*, 17, accessed January 24, 2018, http://www.bazelon.org/wp-content/uploads/2017/01/voting-rights-guide-2016.pdf.
265 Ibid.
266 52 U.S.C. § 10101 (2017).
267 Rabia Belt, "Contemporary Voting Rights Controversies Through the Lens of Disability," *Stanford Law Review* 68: 1506.

268 Katharine Quarmby, "Disabled and Fighting for a Sex Life," *The Atlantic*, March 11, 2015, accessed January 24, 2018, https://www.theatlantic.com/health/archive/2015/03/sex-and-disability/386866/.
269 Robert Dinerstein, *Sexual Expression for Adults with Disabilities: The Role of Guardianship*, accessed January 24, 2018, https://ici.umn.edu/products/impact/232/10.html.
270 American Association on Intellectual and Developmental Disabilities, "Sexuality," A*merican Association on Intellectual and Developmental Disabilities*, accessed January 24, 2018, https://aaidd.org/news-policy/policy/position-statements/sexuality#.WXDCDxXyvct.
271 National Guardianship Association, *Standards of Practice* (2013), 10, accessed July 20, 2017, https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standards-with-Summit-Revisions-2017.pdf.
272 Erika Harrell, *Crime against Persons with Disabilities, 2009–2015—Statistical Tables* (Bureau of Justice Statistics, 2017), 4, accessed January 24, 2018, https://www.bjs.gov/content/pub/pdf/capd0915st.pdf.
273 National Public Radio, "Abused and Betrayed," Special series, accessed January 24, 2018, https://www.npr.org/series/575502633/abused-and-betrayed.
274 National Council on Disability, *Foreign Policy and Disability: Legislative Strategies and Civil Rights Protections to Ensure Inclusion of People with Disabilities*, 16A, September 9, 2003, accessed January 24, 2018, https://www.ncd.gov/rawmedia_repository/38402a3d_fead_4182_84cb_7558dd07e190.pdf.
275 *In re Guardianship of Atkins*, 868 N.E.2d 878, 880-90 (Ind. App. 2007).
276 Aaron Smith and Monica Anderson, "5 Facts About Online Dating," *Pew Research Center*, February 29, 2016, accessed January 24, 2018, http://www.pewresearch.org/fact-tank/2016/02/29/5-facts-about-online-dating/.
277 *Planned Parenthood v. Casey*, 505 U.S. 833, 851 (1992) (holding that the rights to personal dignity and autonomy are central to the liberty protected by the Fourteenth Amendment).
278 *See Cleburne v. Cleburne Living Ctr.*, 473 U.S. 432, 447 (holding that individuals with intellectual disabilities retain their substantive constitutional rights).
279 Alexander A. Boni-Saenz, "Sexuality and Incapacity," *Ohio State Law Journal* 76 (2015): 1208.
280 National Guardianship Association, *Standards of Practice* (2013), 10, accessed July 20, 2017, https://www.guardianship.org/wp-content/uploads/2017/07/NGA-Standards-with-Summit-Revisions-2017.pdf.
281 Sally Balch Hurme, Crossing State Lines: Issues and Solutions in Interstate Guardianship, 37 Stetson L. Rev. 87.
282 Uniform Law Commission, *Adult Guardianship and Protective Proceedings Jurisdiction Act*, accessed January 24, 2018, http://www.uniformlaws.org/Act.aspx?title=Adult%20Guardianship%20and%20Protective%20Proceedings%20Jurisdiction%20Act.
283 Reveal from The Center for Investigative Reporting, *A Mountain of Misconduct*, accessed January 24, 2018, https://www.revealnews.org/episodes/a-mountain-of-misconduct/.
284 U.S. Congress, 1992, Rehabilitation Facilities for People with Head Injuries Hearing before the Subcom on Human Resources and Intergovernmental Relations, House Committee on Government Operations, 102nd cong.
285 Reveal from The Center for Investigative Reporting, *A Mountain of Misconduct*, accessed January 24, 2018, https://www.revealnews.org/episodes/a-mountain-of-misconduct/.
286 Jenica Cassidy, Pamela Teaster, and Erica Wood, *Restoration of Rights in Adult Guardianship: Research & Recommendations* (2017), 6, accessed January 29, 2018, https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf.
287 Ibid., 9.
288 Ibid., 53
289 Ibid., 55.
290 Ibid.
291 Ibid., 51.
292 Kentucky P&A, *Publications*, accessed January 24, 2018, http://www.kypa.net/publications.html.

293 Jenica Cassidy, Pamela Teaster, and Erica Wood, *Restoration of Rights in Adult Guardianship,* accessed January 29, 2018, https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf.

294 Jenica Cassidy, "State Statutory Authority for Restoration of Rights in Termination of Adult Guardianship," *Bifocal* 34, no. 6 (July/August 2013): 125, accessed January 24, 2018, https://www.americanbar.org/content/dam/aba/publications/bifocal/BIFOCALJuly-August2013.authcheckdam.pdf.

295 Jenica Cassidy, Pamela Teaster, and Erica Wood, *Restoration of Rights in Adult Guardianship*, accessed January 29, 2018, https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf.

296 *Olmstead v. L.C. ex rel Zimring*, 527 U.S. 581, 581-82, 607 (1999).

297 Leslie Salzman, "Rethinking Guardianship (Again): Substituted Decision Making as a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," *University of Colorado Law Review* 81 (Winter 2010): 245.

298 Am. Bar Ass'n, *Practical Tool for Lawyers: Steps In Supported Decision Making* (2016), accessed January 24, 2018, http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html.

299 TSYS, *2016 U.S. Consumer Payment Study*, 12, 2016, accessed January 24, 2018, http://www.tsys.com/Assets/TSYS/downloads/rs_2016-us-consumer-payment-study.pdf.

300 National Disability Institute, *Banking Status and Financial Behaviors of Adults with Disabilities: Findings from the FDIC National Survey of Unbanked and Underbanked Households*, 2, April 30, 2015, accessed January 24, 2018, https://www.realeconomicimpact.org/data/files/reports/ndi_banking_status_financial_behaviors_report_2015.pdf.

301 Board of Governors of the Federal Reserve System, Commodity Futures Trading Commission, Consumer Financial Protection Bureau, Federal Deposit Insurance Corporation, Federal Trade Commission, National Credit Union Administration, Office of the Comptroller of the Currency, Securities and Exchange Commission, *Interagency Guidance on Privacy Laws and Reporting Financial Abuse of Older Adults*, September 24, 2013, accessed January 24, 2018, http://files.consumerfinance.gov/f/201309_cfpb_elder-abuse-guidance.pdf.

302 Ibid., 4.

303 Nina Kohn, Jeremy Blumenthal, and Amy Campbell, "Supported Decision-Making," 117; Marshall Kapp, "Health Care Decision Making," in *Aging, Rights and Quality of Life: Prospects for Older People with Developmental Disabilities*, edited by Stanley Herr (Baltimore: Paul H. Brookes Publishing Company, 1999), 45, 53.

304 Sherry Rudy, "Letter from the Chair: Licenses to Steal," *Elder Law Section and Committee Newsletter*, Illinois State Bar Association, 10, no. 3 (March 2005).

305 Linda S. Whitton, "Durable Powers as an Alternative to Guardianship: Lessons We Have Learned," 37 Stetson L. Rev. 7.

306 Lori A. Stiegel & Ellen VanCleave Klem, "Power of Attorney Abuse: What States Can Do About It," *AARP Pub. Pol'y Inst.* 5 (Nov. 2008), accessed January 24, 2018, http://assets.aarp.org/rgcenter/consume/2008_17_poa.pdf.

307 Florida Developmental Disabilities Council, Inc, *Lighting the Way to Guardianship and Other Decision-Making Alternatives: A Manual for Individuals and Families* (2010), 23, accessed January 24, 2018, http://www.fddc.org/sites/default/files/file/publications/Guardianship%20Family%20Manual_0.pdf.

308 Ibid., 24.

309 Jennifer Field, "Special Needs Trusts: Providing for Disabled Children without Sacrificing Public Benefits," *Journal of Juvenile Law* 24 (2003–2004): 89.

310 Florida Developmental Disabilities Council, Inc., *Lighting the Way to Guardianship and Other Decision-Making Alternatives: A Manual for Individuals and Families* (2010), 71, accessed January 24, 2018, http://www.fddc.org/sites/default/files/file/publications/Guardianship%20Family%20Manual_0.pdf.

311 GAO-13-473 SSA Representative Payee Program (May 2013).

312 Testimony of the Honorable Patrick P. O'Carroll, Inspector General, SSA, House Committee on Ways and Means, Hearing on Protecting Social Security from Waste, Fraud, and Abuse, May 18, 2016.
313 *Canterbury v. Spence*, 464 F.2d 772, 783 (D.C. Cir. 1972).
314 Health Insurance Portability and Accountability Act of 1996, Pub.L. No. 104–191, 110 Stat. 1936.
315 Eileen Morrison, *Ethics in Health Administration: A Practical Approach for Decision Makers*, 2nd ed. (Sudbury, MA: Jones and Bartlett, 2011), 92.
316 Ellen A. Callegary, "Guardianship and its Alternatives in the 21st Century," *Maryland Bar Journal* 47 (May/June 2014): 20–21.
317 Health care Roundtable.
318 Ibid., 4.
319 Fla. Stat. §765.401 (2017).
320 Office of Special Education And Rehabilitative Services United States Department Of Education, *A Transition Guide to Postsecondary Education And Employment For Students And Youth With Disabilities* (January 27, 2017), accessed January 24, 2018, https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf.
321 Conn. Agencies Regs. § 10-76d-12 (Lexis Advance through the amendments effective July 10, 2017).
322 Piers Gooding, "Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law," *Psychiatry, Psychology and The Law* 20, no. 3 (2013): doi: 431-5/13218719.2012.711683 (quoting Article 12 of the CRPD, 2006).
323 United Nations Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.C. 3., art. 4(1)(a)-(b).
324 Peter Blanck and Jonathan Martinis, "The Right to Make Choices: The National Resource Center for Supported Decision-Making," *Inclusion* 3, no. 1 (2015): 26–27.
325 United Nations Convention on the Rights of Persons with Disabilities, Article 12, December 13, 2006, 2515 U.N.T.C. 3; Piers Gooding, "Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law," *Psychiatry, Psychology and The Law* 20, no. 3 (2013): 431–451, doi: 10.1080/13218719.2012.711683 (quoting Article 12 of the CRPD, 2006).
326 Cliona de Bhailis and Eilionoir Flyn, "Recognising legal capacity: Commentary and analysis of Article 12 CRPD," *International Journal of Law in Context* 12, no. 1 (2017): 6021.
327 Robert D. 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," *Human Rights Brief* 19 (2012): 8–12.
328 Ibid.; Blanck and Martinis, "The Right to Make Choices," 24–33; Quality Trust for Individuals with Disabilities, Burton Blatt Institute, and Council on Quality and Leadership, *Supported Decision-Making: An Agenda for Action* (2003): 1–11, accessed January 24, 2018, http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf.
329 Dinerstein, "Implementing Legal Capacity," 10; Michael Bach, "Securing Self-Determination: Building the Agenda in Canada," *TASH Newsletter*, June/July 1998, 7–10.
330 Blanck and Martinis, "The Right to Make Choices," 24–33; Campanella, "Supported Decision-Making in Practice," 35–39; Kristin Booth Glen, "Supported Decision-Making and the Human Right of Legal Capacity," *Inclusion* 3, no. 1 (March 2015): 2–16; Kohn, Blumenthal, and Campbell, "Supported Decision-Making," 1111–1157; Bach, "Securing Self-Determination," 7–10.
331 Michael L. Wehmeyer, Susan B. Palmer, Martin Agran, Dennis E. Mithaug, and James E. Martin, "Promoting Casual Agency: The Self-Determined Learning Model of Instruction," *Exceptional Children* 66, no. 4 (2000): 400.
332 Yves Lachapelle, et al., "The Relationship Between Quality of Life and Self-Determination: An International Study," *Journal of Intellectual Disability Research* 49 (2005): 740–744, doi: 10.1111/j.1365-2788.2005.00743.x; Michelle Schwartz and Michael Wehmeyer, "Self Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities," *Exceptional Children* 63, no. 2 (1997):

245–255; Michael L. Wehmeyer and Susan B. Palmer, "Adult Outcomes for Students with Cognitive Disabilities Three-Years After High School: The Impact of Self-Determination," *Education and Training in Developmental Disabilities* 38, no. 2 (2003): 131–144, doi: 10.1177/0022466913489733; Ishita Khemka, Linda Hickson, and Gillian Reynolds, "Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse," *American Journal on Mental Retardation* 110 (2005): 193–204, doi: 10.1352/0895-8017(2005)110<193:EOADCD>2.0.CO.

333 Michael Wehmeyer, "Self-Determination and the Education of Students with Disabilities," Hoagies' Gifted Education Page, last modified September 2002, accessed January 24, 2018, http://www.hoagiesgifted.org/eric/e632.html.

334 Brian P. O'Connor and Robert J. Vallerand, "The Relative Effects of Actual and Experienced Autonomy on Motivation in Nursing Home Residents," Canadian Journal on Aging 13 (1994): 528–538, doi: 10.1017/S0714980800006371.

335 Mary Jane Ciccarello and Maureen Henry, "WINGS: Person-Centered Planning and Supported Decision-Making," *Utah Bar Journal* 27, no. 3 (2014): 49–50.

336 Laurie E. 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," *Children and Youth Services Review* 34, no. 11 (2012): 2179–2187, doi: 10.1016/j.childyouth.2012.07.018.

337 Shogren, et al., "Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities," 256–267; Schwartz and Wehmeyer, "Self-determination and Positive Adult Outcomes," 245–255.

338 B.J. Winick, "The Side-Effects of Incompetency Labeling and the Implications for Mental-Health Law," *Psychology, Public Policy, and Law* 1 (1995): 21.

339 Jennifer L. Wright, "Guardianship for Your Own Good: Improving the Well-Being of Respondents and Wards in the USA," *International Journal of Law & Psychiatry* 33 (2010): 354.

340 Office of the Public Advocate, Systems Advocacy, *A Journey Towards Autonomy? Supported Decision-Making in Theory and in Practice*, 1–32, February 2014, accessed January 24, 2018, http://www.justice.qld.gov.au/__data/assets/pdf_file/0005/249404/Decision-making-support-for-Queenslanders-with-impaired-capacity-A-review-of-literature-March-2014.pdf; Christina Bigby, Mary Whiteside, and Jacinta Douglas, *Supporting People with Cognitive Disabilities in Decision Making—Processes and Dilemmas* (2015), 2–3, accessed January 24, 2018, http://hdl.handle.net/1959.9/510567.

341 Hatch, Crane, and Martinis, "Unjustified Isolation Is Discrimination: The *Olmstead* Case Against Overbroad and Undue Organizational and Public Guardianship," 65–74; *see also* Salzman, "Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act," *University of Colorado Law Review* 81 (2010): 221–231.

342 Individuals with Disabilities Education Act, P.L. 91–230, 84 Stat. 175; Kanter, "Guardianship for Young Adults with Disabilities as a Violation of the Purpose of the Individuals with Disabilities Education Improvement Act," 61.

343 Rehabilitation Act of 1973, P.L. 93–112, 87 Stat. 355; Jonathan Martinis, "'The Right to Make Choices': How Vocational Rehabilitation Can Help Young Adults with Disabilities Increase Self-Determination and Avoid Guardianship," *Journal of Vocational Rehabilitation* 42, no. 3 (2015): 221–227.

344 Ciccarello and Henry, "WINGS: Person-Centered Planning," 48.

345 Nina A. Kohn and Jeremy A. Blumenthal, "A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities," *Disability and Health Law Journal* 7, no. 1 (January 2014): 541; Salzman, "New Perspectives on Guardians and Mental Illness," 306.

346 Kohn and Blumenthal, "A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities," 541; *see also* Salzman, "New Perspectives on Guardians and Mental Illness," 309; Krista James and Laura Watts, *Understanding the Lived Experiences of Supported Decision-Making in Canada: Legal Capacity, Decision-Making, and Guardianship*, 8, March 2014, accessed January 24, 2018, http://www.lco-cdo.org/wp-content/uploads/2014/03/capacity-guardianship-commissioned-paper-ccel.pdf.

347 Carney, "Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?," 62.

348 Ibid.
349 Sean Burke, "Person-Centered Guardianship: How the Rise of Supported Decision-Making and Person-Centered Services Can Help *Olmstead*'s Promise Get Here Faster," *Mitchell Hamline Law Review* 42, no. 3 (2016): 879; Rebekah Diller, "Legal Capacity for All: What the Shift from Adult Guardianship to Supported Decision-Making Has to Offer Older Adults," *Fordham Urban Law Journal* 43 (forthcoming 2017; on file with authors); *but see* Brake, "Supported Decision-Making in the Elder Law Practice: Promoting the Aging Client's Right to Legal Capacity," 1–9.
350 James and Watts, "Understanding the Lived Experiences of Supported Decision-Making in Canada," 8.
351 Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 13.
352 United Nations, "From Provisions to Practice: Implementing the Convention, Legal Capacity and Supported Decision-Making," in *UN Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities* (2007), 1–110, accessed January 24, 2018, http://www.ipu.org/PDF/publications/disabilities-e.pdf.
353 Ibid.
354 Administration for Community Living, "Preserving the Right to Self-determination: Supported Decision-Making" (January 28, 2015), accessed January 24, 2018, https://www.acl.gov/news-and-events/acl-blog/preserving-right-self-determination-supported-decision-making.
355 United Nations, "From Provisions to Practice: Implementing the Convention, Legal Capacity and Supported Decision-Making," in *UN Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities* (2007), 1–110, accessed January 24, 2018, http://www.ipu.org/PDF/publications/disabilities-e.pdf.
356 Dinerstein, Grewal, and Martinis, "Emerging International Trends," 442.
357 J. Matt Jameson, et al., "Guardianship and the Potential of Supported Decision Making with Individuals with Disabilities," *Research and Practice for Persons with Severe Disabilities* 40, no. 1 (March 1, 2015): 3.
358 National Guardianship Association, "Position State on Guardianship, Surrogate Decision Making, and Supported Decision-Making" (May 2016), 1–2, accessed August 7, 2017, https://www.guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf.
359 Johns, "Person-Centered Planning in Guardianship: A Little Hope for the Future," 1544.
360 Convention on the Rights of Persons with Disabilities, G.A. Res. 61/106 (Dec. 12. 2006).
361 Dinerstein, Tales from a Supportive Guardianship, 53(2) *Court Review: The Journal of the American Judges Association* 25–37 (forthcoming 2017).
362 Proposed Nat'l Conference of Comm'rs on Unif. State Laws, Unif. Guardianship, Conservatorship, and other Protective Arrangements Act § 301(b) (June 2017 draft).
363 Dinerstein, Grewal, and Martinis, "Emerging International Trends and Practices in Guardianship Law for People with Disabilities," 425; Terry Carney, "Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?," *Laws* 4 (2015): 37–149.
364 Autistic Self Advocacy Network, "The Right to Make Choices: International Laws and Decision-Making by People with Disabilities," last modified February 1, 2016, accessed January 24, 2018, http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/.
365 Leslie Salzman, "New Perspectives on Guardians and Mental Illness: Guardianship for Persons with Mental Illness—A Legal and Appropriate Alternative?," *St. Louis University Journal of Health Law & Policy* 4 (2011): 307–309.
366 Ibid.
367 Office of the Public Advocate, Australia, *Supported Decision Making*, accessed January 24, 2018, http://www.opa.sa.gov.au/resources/supported_decision_making.
368 Ibid.; Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 10.
369 Dinerstein, Grewal, and Martinis, "Emerging International Trends," 452.
370 Dinerstein, "Implementing Legal Capacity," 9–10.
371 Ibid., 10.

372 *See In re Ryan King*, 2003 INT 249, PIN CITE (D.C. Super. Ct. 2016); *Matter of Michelle M.*, 2016 N.Y. Misc. LEXIS 2719, at *PIN CITE (Kings Cty Sur. Ct., 2016); *Matter of Hytham M.G.*, 2016 N.Y. Misc LEXIS 2722, at *PIN CITE (Kings Cty. Sur. Ct. 2016); *In re CC*, Berkshire County Probate Court; Pittsfield, MA (November 11, 2015, http://supporteddecisions.org/cory/); *Ross v. Hatch*, No. CWF120000426P-03, slip op. at 17 (*Newport News*, Va. Cir. Ct. Aug. 2, 2013)); *In re Guardianship of Dameris L.*, 956 N.Y.S.2d 848, PIN CITE (N.Y. Cty. Sur. Ct. 2012); *In re SCPA Article 17-A Guardianship Proceeding for Mark C.H., Ward*, 906 N.Y.S.2d 419, PIN CITE (N.Y. Cty. Sur. Ct. 2010); *In re Peery*, 727 A.2d 539, 540 (Pa. 1999). *See also* Consent Order for M.M. (Florida, 10/13/16, described at http://www.disabilityrightsflorida.org/podcast/story/episode_5_supported_decision_making); *In re C.B.,* Stipulation to Dismiss Guardianship (Superior Court, Orleans Unit, Vermont, April 11, 2017).

373 Dinerstein, Grewal, and Martinis, "Emerging International Trends," 455–456.

374 Tex. Est. Code Ann. § 1357.056 (West 2017).

375 Del. Code Ann. tit. 16, §§ 9401a-9410a (2017).

376 D.C. Act 20-486 (effective March 2015) ("[S]tudent[s] who ha[ve] reached 18 years of age may receive support . . . to aid them in their decision-making"); *see also* D.C. Public Schools Transfer of Rights Guidelines (Aug. 2013) (recognizing SDM and advancing use of an SDM Form); D.C. Mun. Regs. tit. 5-E §§ 3001, 3004 (effective July 1, 2016) (recognizing SDM as an alternative to guardianship across all publicly funded schools in D.C.).

377 Md. Code Ann. Health—Gen. § 20-1601 (incorporating SDM in the medical context concerning nondiscrimination in access to organ transplantation).

378 H.J. Res. 190, 2014 Leg., Reg. Sess. (Va. 2014) (ordered study of SDM, which, when complete, recommended SDM be implemented in all service systems).

379 H.B. 900, 127th Leg., 2nd Reg. Sess. (Me. 2016) (resolving that the Probate and Trust Law Advisory Commission will examine SDM and make recommendations about inclusion within Probate Code, with report due January 15, 2017).

380 S. Res. 44 , 120th Gen. Assemb., 1st Reg. Sess. (In. 2017)

381 *See*, e.g., D.C. Bill 22-0154, Council Period 22 (2017) (proposing codification of a Supported Decision-Making Agreement form); S.B. 264, 110th Gen. Assemb., 1st Reg. Sess. (Tenn. 2017); H.B. 941, 110th Gen. Assemb., 1st Reg. Sess. (Tenn. 2017) (proposing recognition of SDM agreements); H.B. 713, 2017 Gen. Assemb., Reg. Sess. (N.C. 2017) (proposing direction of legislative research commission to study supported decision-making as an alternative to guardianship); S.B. 748, 85th Leg. (Tex. 2017) (proposing an SDM requirement in special education transition planning, and was sent to the Governor May 28, 2017); H.B. 2343, 87th Leg., Reg. Sess. (Kan. 2017) (proposing recognition of SDM in the context of organ transplantation); H.B. 21, 149th Gen. Assemb., 1st Reg. Sess. (Del. 2017) (similar to the aforementioned Kansas legislation); S.B. 5447, 65th Leg., Reg. Sess. (Wash. 2017); H.B. 1139, 65th Leg., Reg. Sess. (Wash. 2017) (proposing a requirement that the public guardian administrator establish an SDM assistance program); and Assemb. B. 437, Reg. Sess. (Cal. 2017) (proposing to define SDM within the context of a Voluntary Online At-Risk Community Network).

382 Human Services Research Institute, *Supported Decision-Making Pilot: A Collaborative Approach*, *Pilot Evaluation Year 1 Report,* 1-47, November 30, 2015, accessed January 24, 2018, http://supporteddecisions.org/wp-content/uploads/2015/04/SDM-Evaluation-Report-Year-1_HSRI-2015.pdf; Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 2–16.

383 Disability Rights Maine, SupportMyDecision.org, accessed July 18, 2017, http://supportmydecision.org/; First in Families of North Carolina, "Lifetime Connections," accessed July 18, 2017, http://www.fifnc.org/programs/connections.html (describing the work of North Carolina's SDM coalition).

384 Glen, "Supported Decision-Making," 8; Developmental Disabilities Planning Council, "Supported Decision-Making," New York State, accessed January 24, 2018, http://ddpc.ny.gov/supported-decision-making-0 (describing the New York SDM pilot program).

385 Texas Department of Aging and Disability Services, *Volunteer-Supported Decision-making for People with Cognitive Impairments: A Report on the San Angelo Alternatives to Guardianship Project*, 1–9, December

2012, accessed July 18, 2017, http://www.tcdd.texas.gov/projects/grants-completed-projects/the-arc-of-san-angelo/; Texas Law INCLUDE Project, "Texas Law INCLUDE Project," Texas Law, accessed January 24, 2018, https://law.utexas.edu/probono/opportunities/texas-law-include-project/.

386 Jessalyn Gustin and Jonathan Martinis, "Vermont to Change Culture of Disabilities," *Apostrophe*, September 27, 2016, accessed January 24, 2018, http://apostrophemagazine.com/vermont-change-culture-disabilities/.

387 Blanck and Martinis, "The Right to Make Choices," 28–31.

388 *See* ABA Commission on Law and Aging, *PRACTICAL Tool for Lawyers: Steps in Supporting Decision-Making and Resource Guide* (2016), 1, 6, accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/law_aging/PRACTICALTool.authcheckdam.pdf.

389 *See* National Guardianship Association, *Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making*, 2015, accessed July 19, 2017, https://www.guardianship.org/wp-content/uploads/2017/07/SDM-Position-Statement-9-20-17.pdf. ("Supported decision making should be considered for the person before guardianship, and the supported decision-making process should be incorporated as a part of the guardianship if guardianship is necessary.")

390 Social Security Advisory Board, *Representative Payees: A Call to Action*, March 2016, accessed January 24, 2018, http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf (recognizing SDM as an alternative to SSA appointment of representative payee); Advisory Committee on Increasing Competitive Integrated Employment for People with Disabilities, *Final Report*, 53–54, September 15, 2016, accessed January 24, 2018, https://www.dol.gov/odep/topics/pdf/ACICIEID_Final_Report_9-8-16.pdf (endorsing supported decision-making as a method of equipping people with disabilities "with the knowledge, skills, abilities, and tools they need to succeed . . .").

391 *See* U.S. Department of Education, Office of Special Education Rehabilitation Services, *A Transition Guide to Postsecondary Education and Employment for Students with Youth and Disabilities*, 1–40, January 2017, accessed January 24, 2018, https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf (includes section on "Parental Consent, Age of Majority, Supported Decision-Making and Guardianship").

392 American Bar Association Commission on Disability Rights and American Bar Association Commission on Law and Aging, *Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual Disabilities* (2012), accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/administrative/mental_physical_disability/SDMRoundtable_Summary.authcheckdam.pdf (providing a short summary of the roundtable discussion).

393 Quality Trust, *Supported Decision-Making*, 1–11; Blanck and Martinis, "The Right to Make Choices," 28.

394 Martinis and Gustin, "Supported Decision-Making as an Alternative to Overbroad and Undue Guardianship," 41–44.

395 American Bar Association Adopted by the House of Delegates, *Resolution*, August 14–15, 2017 accessed January 24, 2018, http://www.americanbar.org/content/dam/aba/directories/policy/2017_am_113.docx.

396 Uniform Law Commission, "Guardianship, Conservatorship, and Other Protective Arrangements Act Committee," accessed January 24, 2018, http://www.uniformlaws.org/Committee.aspx?title=Guardianship,%20Conservatorship,%20and%20Other%20Protective%20Arrangements%20Act.

397 Kohn, Blumenthal, and Campbell, "Supported Decision-Making," 1111–1157; Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 13; Burke, "Person-Centered Guardianship," 885–886; Office of the Public Advocate Systems Advocacy, *A Journey Towards Autonomy*, 1–32; Bigby, Whiteside, and Douglas, *Supporting People with Cognitive Disabilities in Decision Making*, 2–3.

398 Pathare and Shields, "Supportive Decision-Making for Persons with Mental Illness," 31.

399 James and Watts, "Understanding the Lived Experiences of Supported Decision-Making in Canada," 3–81; Kohn, Blumenthal, and Campbell, "Supportive Decision-Making," 1111–1157; Office of the Public Advocate Systems Advocacy, *A Journey Towards Autonomy*, 1–32; Kohn and Blumenthal, "A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities," 540–543.

400 Kohn and Blumenthal, "A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities," 541.
401 Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 13.
402 Blanck and Martinis, "The Right to Make Choices," 29.
403 Leslie Salzman, "New Perspectives on Guardians and Mental Illness: Guardianship for Persons with Mental Illness— A Legal and Appropriate Alternative?," *St. Louis University Journal of Health Law & Policy* 4 (2011): 310
404 Carney, "Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?," 63; Bigby, Whiteside, and Douglas, *Supporting People with Cognitive Disabilities in Decision Making*, 2–3.
405 Bigby, Whiteside, and Douglas, *Supporting People with Cognitive Disabilities in Decision Making*, 2–3.
406 James and Watts, "Understanding the Lived Experiences of Supported Decision-Making in Canada," 8.
407 Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 2–16.
408 Inclusion Europe, *Key Elements of a System for Supported Decision-Making: Position Paper of Inclusion*, 1–5, accessed January 24, 2018, http://inclusion-europe.eu/wp-content/uploads/2015/03/15.Position_Supported_Decision_Making_EN.pdf (Adopted at General Assembly 2008).
409 Shih-Ning Then, "Evolution and Innovation in Guardianship Laws: Assisted Decision-Making," *Sydney Law Review* 35 (2013): 161–162.
410 Jalayne J. Arias, "A Time to Step In: Legal Mechanisms for Protecting Those with Declining Capacity," *American Journal of Law and Medicine* 39 (2013): 157; Glen, "Supported Decision-Making and the Human Right of Legal Capacity," 11–12.
411 Ibid.
412 Then, "Evolution and Innovation in Guardianship Laws," 165–166.
413 Carney, "Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?," 37–59.
414 Kohn and Blumenthal, "A Critical Assessment of Supported Decision-making for Persons Aging with Intellectual Disabilities," 542; Jameson, et al., "Guardianship and Potential of Supported Decision-Making," 1–16.
415 CRPD Article 12.
416 Given this was a national project involving people living in various states across the country, all with variable consent laws, the decision was made to take a conservative approach and, when a person was determined to be subject to guardianship, obtain the guardian's approval for the interview to move forward. There also were two occasions where the guardians terminated the interview after it started, so those interviews were not able to be used as part of this report.
417 Please note that there were cases in which a participant was identified to participate as a representative of one category and, during the course of the interview, it became apparent they actually fit into multiple categories (e.g., a professional who was also a family member of a person with a disability).
418 The law student interviewers included Allison Mazzei, Myra Reyes, Abigail Silverman, and Emily Wolfford.

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004