Turning Rights Into Reality:

How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities

National Council on Disability

June 10, 2019

National Council on Disability (NCD)
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Washington, DC 20004

Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities

National Council on Disability, June 10, 2019
Celebrating 30 years as an independent federal agency

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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

June 10, 2019

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

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit this report, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* as a follow-up to a report that was completed last year, *Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities*, which offers policy research and recommendations for the consideration of your Administration and Congress. This report provides a more in-depth examination of the unique challenges faced by individuals with intellectual and developmental disabilities (ID/DD), and how the use of alternatives such as supported decision-making may enable some individuals with ID/DD to exercise greater self-determination, participate more fully in their communities, and achieve greater economic self-sufficiency.

In this report, NCD examines why people with ID/DD are at increased risk for becoming subject to guardianship as adults, and how that impacts their ability to benefit from civil rights laws aimed at advancing the self-determination and opportunities available to people with ID/DD, including the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Developmental Disabilities Act, and the Workforce Innovation and Opportunity Act. The report also examines how people with ID/DD are treated differently than other adults who are the subjects of guardianship proceedings, including in several states that have separate guardianship laws for people with ID/DD. Finally, the report examines the available data on guardianship for people with ID/DD and highlights the stories of people with ID/DD in the nation's capital to increase policymakers' understanding of the impact of guardianship and alternatives to guardianship on the lives of people with ID/DD.

We hope that this report will increase the understanding of guardianship and its impact in the lives of people with ID/DD and their families across the Administration and in Congress. The report includes recommendations for the Social Security Administration, as well as the U.S. Departments of Education, Justice, and Health and Human Services. NCD stands ready to work with you and your Administration to ensure that Americans with ID/DD are provided with viable alternatives to guardianship if they need decision-making assistance, and that the due process

protections they are afforded when they are faced with a petition for guardianship are robust and will avoid the unnecessary removal of civil rights.

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 House of Representatives.)

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Glossary

ABLE Accounts: A type of tax-advantaged savings account, established under the Achieving a Better Life Experience (ABLE) Act of 2014, for people with significant disabilities that began before they turned 26 and who meet the Social Security Administration's (SSA) definition of disability. Eligible individuals who are the owner and designated beneficiary of the ABLE account can use funds from the account to pay for qualified disability expenses, which are defined in the ABLE Act and its regulations. The first $100,000 in ABLE accounts are exempted from the individual's resource limit for Supplemental Security Income (SSI). ABLE accounts are disregarded for the purpose of determining if a person meets the asset limit for Medicaid. For more information, visit http://ablenrc.org/.

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.

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 the person becomes *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 filed by a guardian of the property that some states require to be submitted to the court each year itemizing expenditures and receipts made on behalf of the person. 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 in 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, Attorneys ad Litem do not necessarily advocate for the desired outcome of the individual they represent, but they may advocate for an outcome the Attorney ad Litem deems is in the person's best interest.

Best Interest: A type of decision-making standard that may be used when deciding on behalf of another person, particularly in court cases involving child custody or welfare. Compared to *Substituted Judgment*, the Best Interest standard tends to prioritize the person's safety and well-being, rather than their expressed wishes. While traditionally linked with decisions made by guardians, it is now considered the less-preferred decision-making standard. For example, the National Guardianship Association's standards indicate that, "only when the person's goals and preferences cannot be ascertained, may the guardian make a decision in the person's best interest."[1]

Capacity: An individual's ability to perform a specific task, such as to sign a contract. The term 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."

Case Management Services: Coordinating services through community and government agencies, the extent of which depends on the specific state.

Clerk of the Court: A court officer responsible for filing papers, administering 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: A person appointed by a court 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 in 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* and unable to make decisions. The agent appointed by the principal in a durable power of attorney can continue to act within the scope of authority granted under this legal document.

Family Guardian: A non-professional guardian who serves as guardian for an individual. Although family guardians usually are related to the individual, they may be friends or even volunteers. Although they may be able to be reimbursed out of the individual's estate, family guardians do not serve 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 regarding guardianship for minors and adults. 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.

Incapacitated: 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. 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."[2] However, the concept of capacity is a social and legal construct that is not necessarily provable or disprovable through scientific methods, and the use of the terms "capacity" and "incapacity" is becoming disfavored by guardianship reformers. For example, the 2017 Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act[3] makes no reference to either term.

Indigent: An individual with little to no resources 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.

Joint Ownership: A situation in which two or more people co-own property. It allows a co-owner of land or bank accounts to manage an *incapacitated* co-owner's property as their own.

Limited Guardianship: A guardianship where the guardian only has the authority specifically given by court order. The person in 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. A Magistrate Judge generally handles minor cases and, in some jurisdictions, may handle guardianships cases, especially those that are uncontested.

Money Management Services: Services that help people with their financial affairs such as check depositing and writing, bill paying, budgeting and checkbook balancing, and tax preparation. Money Management Services are voluntary, so the person must be able to ask for or accept them.

Physician Orders of Life-Sustaining Treatment ("POLST"): The POLST process requires a discussion between the treating health care practitioner and the person about key end-of-life care treatment options, so that the person's wishes can be identified and incorporated into doctor's orders kept in the medical record or with the person. Those orders are reviewed periodically and must travel with the patient whenever he or she moves from one setting to another, thereby promoting continuity of care.

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

Power of Attorney: A legal document executed under state law whereby one person (called the *principal*) voluntarily designates someone else (called the *attorney-in-fact* or *agent*) to legally act on their behalf for certain decisions and in certain circumstances. A *durable power of attorney* continues even after the individual has lost capacity. A *power of attorney for health care* usually goes into effect when the person becomes incapacitated.

Professional Guardian: A professional guardian is generally a private individual or organization who serves as guardian for numerous individuals and is not a member of those individuals' families. Professional guardians 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 or local government 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 governmental 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 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 if 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 deciding on behalf of an individual in a manner 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*.

Supported Decision-Making: There is no singular definition or model, but this generally means an individual choosing one or more people to assist that person in understanding the nature and consequences of potential personal and financial decisions, supporting the individual in making their own decisions, and then communicating decisions as needed. 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. This process works in the same way that most adults make daily decisions—by seeking advice, input, and information from trusted knowledgeable others.

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 kinds of trusts, each of which provides different benefits.

Executive Summary

In March 2018, the National Council on Disability (NCD) released a seminal report, "Beyond Guardianship: Toward Alternatives That Promote Greater Self-Determination for People with Disabilities," which provided a comprehensive review of adult guardianship through the lens of civil rights reforms impacting people with disabilities. The report cited serious problems about how guardianship systems function in the United States, including:

- lack of reliable state and national data on guardianship,
- misperceptions about the ability of people with disabilities to make autonomous decisions,
- denial of due process within guardianship proceedings and meaningful consideration of less-restrictive alternatives,
- insufficiencies in capacity determinations,
- lack of court oversight of guardians, and
- inaccessibility and underutilization of rights restoration processes after a guardian is appointed.

In addition to its detailed findings, the 2018 NCD Report offers recommendations for reforms to improve the lives of people with disabilities who may need decision-making assistance. It also suggests reforms to prevent overly broad or undue guardianships, and to improve court oversight of existing guardianships to eliminate abuse, neglect, and exploitation.

The present report builds upon the work of the 2018 NCD report by specifically examining the role of guardianship and other alternatives in the lives of people with intellectual and developmental disabilities (ID/DD), a population that is known to be at increased risk of having guardians. The report also examines if the increased risk for people with ID/DD may be linked to the different ways states apply guardianship laws, as well as biases and/or assumptions about the ability of people with ID/DD to fully experience the dignity of risk.

Some view guardianship as necessary to protect people with ID/DD. Others raise concerns about its stigma and how it impacts the civil rights and personhood of people with ID/DD. Like its predecessor, this report seeks to acknowledge and balance both of those views, while holding to the belief that "people with disabilities both desire and deserve choices when seeking assistance with daily living that maintains their self-determination and maximum dignity and independence."[4]

Summary of Methodology

The 2018 NCD report provided a broad overview of the current state of guardianship law and practice, as well as policy reforms and analysis of how effective or ineffective those efforts have

been. The present report uses that overview as a springboard to explore the experiences of people with ID/DD, their families, and others through a multimodal blend of updated literature review, data analysis, key informant interviews, targeted outreach, and personal story gathering from stakeholders.

This report is organized into six chapters.

- Chapter 1 briefly explains what guardianship is and includes cross-references to the lengthier explanation in the 2018 NCD report. It also introduces the reader to what is meant by ID/DD and how people with ID/DD are at an increased risk for having guardians. It also explains how guardianship, while directly governed by state law, can negatively implicate important federal civil rights for people made subject to it.
- Chapter 2 describes what has become known as the "school-to-guardianship pipeline," as well as its impact on youth with ID/DD. It examines U.S. policy implications of this pipeline under important federal laws, including the Individuals with Disabilities Education Act (IDEA), the Developmental Disabilities Assistance and Bill of Rights Act, the Americans with Disabilities Act (ADA), the Rehabilitation Act, and the Workforce Innovation and Opportunity Act (WIOA).
- Chapter 3 explores how some states' guardianship laws have different standards and processes for obtaining guardianship over people with ID/DD than other populations who may need decision-making assistance. It also discusses the impact of the disparate treatment of people with ID/DD, as well as U.S. policy implications, which include concerns about the lack of procedural and substantive due process and the potential for discrimination based solely on disability diagnosis.
- Chapter 4 acknowledges the 2018 NCD report findings about the lack of reliable and consistent national and state data on guardianship. It includes an analysis based on available National Core Indicator data, which addresses key questions about guardianship and people with ID/DD, including whether or not people with ID/DD who have guardians are more or less likely to live in restrictive environments than those who do not; whether guardianships for people with ID/DD are increasing or decreasing; and what the prevalence is of guardianship broken down by race and general age group.
- Chapter 5 gives an in-depth analysis of guardianship's impact on people with ID/DD within Washington, DC, including never-before-published trends in DC guardianship data and lessons that other states can learn from DC's experience.
- Chapter 6 summarizes the input this project received from stakeholders who responded to our call for their experiences with guardianship and alternatives. This includes people with ID/DD, their family members, and other stakeholders, such as special

education advocates, guardians and administrators of guardianship programs, and staff who provide transition services to youth with ID/DD. To gather information from stakeholders, NCD developed templates to gather input through emails, an online tool, and personal interviews. NCD ultimately received 70 substantive responses from 19 states and the District of Columbia.

- Finally, Chapter 7 offers NCD's findings and recommendations, considering the information presented in this report.

Executive Summary in Plain English

The National Council on Disability (NCD) is a group that works to help the government learn more about how they can help people with disabilities. One way we do this is by writing reports about different topics that are important to people with disabilities, like this one. We wrote this summary in plain English to make it accessible to everyone.

NCD wrote a report about guardianship in March 2018. Guardianship is when someone—like a family member, friend, or paid person—is chosen by the court to make legal decisions for a person. In that report, we looked at rights of adults with disabilities, guardianship, and other ways people make choices in their lives. We found many problems with guardianship in the United States. Sometimes governments and courts think people with disabilities can't make decisions themselves. Sometimes people with disabilities can't ask to change or get rid of their guardian, even if they feel the guardian isn't helping them. Sometimes, they can't report problems with their guardian, or figure out other ways to make decisions without a guardian. Judges don't always pay attention to what the guardians are doing, even if a guardian has caused problems before. But people who have guardians still have some rights. Once a person gets a guardian, they don't always need one forever—but some people don't know that. NCD talked about how to help more people with disabilities make their own decisions, with the support they need and want. We also explained how guardians and courts could do a better job without hurting people with disabilities.

We know that there are many people with intellectual and developmental disabilities who have guardians. We wanted to focus on that, so NCD wrote this second report. We also wanted to know if more people with intellectual and developmental disabilities have guardians now than they did before. States have different guardianship laws, and that can be confusing for people with disabilities, family members, and judges. Sometimes people think that if you have an intellectual and developmental disability, you can't make decisions for yourself. They think you could get hurt, even though everyone makes bad decisions or gets hurt sometimes.

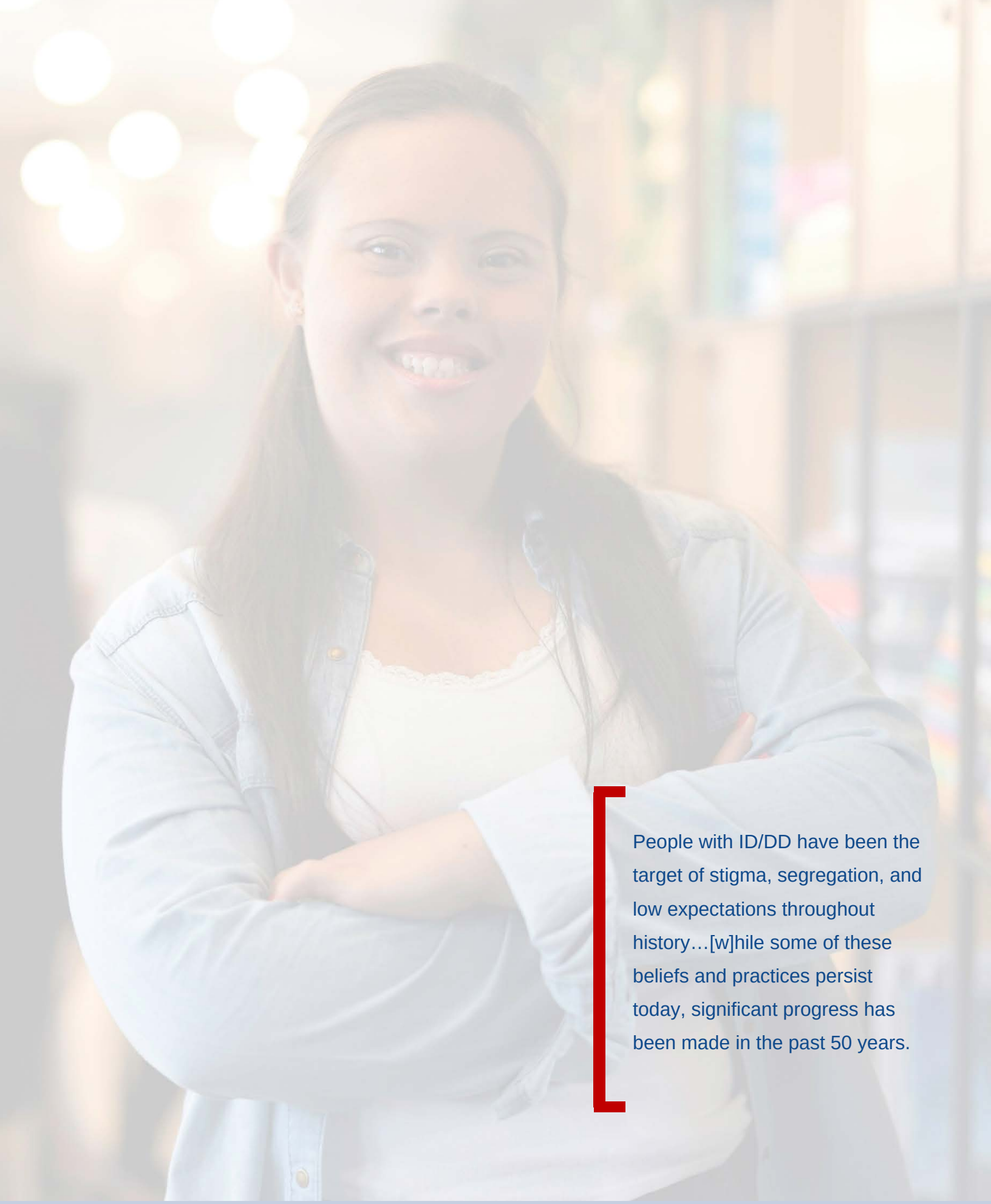
There is a big debate about guardians. Some people think guardians are a really good thing. They can help protect people with intellectual disabilities and help them make decisions. Some people are worried about guardians taking away the rights of people with disabilities or making bad decisions. Some people are embarrassed about having a guardian. NCD believes guardians are not always bad or always good. You should not be embarrassed if you need or want a guardian. But people with intellectual and developmental disabilities should always get to make decisions

about their lives. You should be able to tell other people about any problems you're having. You should always have rights and choices. Sometimes a guardian can help with these things. Other times, a person with an intellectual and developmental disability might not want or need a guardian.

We did a lot of work before we wrote this report. We talked to people with intellectual and developmental disabilities and their families and listened to their stories. We talked to experts who know a lot about guardianship. We read what people wrote about guardianship. After all that, we wrote this report. We came up with a lot of ideas about how guardianship in the United States should be made better for people with intellectual disabilities. We also talked about how other options besides guardianship should be used when they can. We are asking the Federal Government to think and make changes based on our ideas.

List of Acronyms

ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADAA	ADA Amendments Act 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	The Office of Special Education Programs at the U.S. Department of Education
OSERS	The Office of Special Education and Rehabilitative Services at the U.S. Department of Education
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
WIOA	Workforce Innovation and Opportunity Act



People with ID/DD have been the target of stigma, segregation, and low expectations throughout history…[w]hile some of these beliefs and practices persist today, significant progress has been made in the past 50 years.

Chapter 1: Introduction to ID/DD, Guardianship, and Alternatives

People with Intellectual and Developmental Disabilities

The group of people with disabilities addressed in this report are people with intellectual and/or developmental disabilities (ID/DD). According to the American Association on Intellectual and Developmental Disabilities : "Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" and originates before the age of 18.[5] Prior to 2010 and the passage of federal legislation known as "Rosa's Law," intellectual disability was generally referred to as "mental retardation," which advocates with disabilities now consider a pejorative.[6]

While an intellectual disability is usually considered to be a developmental disability, the term "developmental disabilities" refers to a broader group of lifelong disabilities that can be intellectual, physical, or both. Federal law defines developmental disabilities as:

A severe, chronic disability of an individual that: (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) [s]elf-care; (II) [r]eceptive and expressive language; (III) [l]earning; (IV) [m]obility; (V) [s]elf-direction; (VI) [c]apacity for independent living; (VII) [e]conomic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.[7]

People with ID/DD have been the target of stigma, segregation, and low expectations throughout history.

Depending on their functional impact, examples of developmental disabilities under this federal definition may include intellectual disability, autism, cerebral palsy, Down syndrome, fragile X syndrome, fetal alcohol syndrome, spina bifida, and brain injuries occurring before the age of 22, among other disabilities.

People with ID/DD have been the target of stigma, segregation, and low expectations throughout history. It was a widely held belief that people with ID/DD were unable to benefit from typical life experiences or contribute to society in any meaningful way. It also was believed that people with ID/DD needed high levels of supervision and protection throughout their lifetimes.

These beliefs led to people being denied opportunities for education, confined to institutions, and being placed under guardianship primarily based on the presence of an ID/DD-related diagnosis.

While some of these beliefs and practices persist today, significant progress has been made in the past 50 years. The passage of IDEA (then known as the Education for All Handicapped Children Act) in 1975 and the ADA in 1990 were supported by new beliefs about the potential for people with ID/DD to learn, grow, and contribute to society, including equal access to education and human rights. People with ID/DD now are breaking down many of the old stereotypes with support from improved medical knowledge, access to education and technology, and opportunities for full community inclusion and participation.

Debunking Myths of Intelligence Testing of People with ID/DD

Diagnosing ID/DD frequently involves some sort of testing. This testing usually includes tests of intellectual functioning. A person's intellectual functioning is generally determined by the demonstration of certain skills such as the ability to reason, solve problems, and navigate through a variety of life situations. Although intelligence testing has existed since the early 1900s, there has been much controversy within the field of psychology about whether the testing actually measures "intelligence." One of the first of these tests, designed by Alfred Binet, was intended to identify children who might need extra assistance with learning, and was not intended to measure intelligence. Although Binet believed that

intelligence was not fixed and could change over time, future tests building on his original work were developed by people who believed differently. These subsequent tests were frequently used to identify people who were considered less capable and therefore somehow inferior in society. This had the greatest impact on people with ID/DD during what is known as the "eugenics era," where people who were identified as "feeble minded" based on intelligence testing were removed from society, sterilized, and sent to institutions.

While significant scientific debate about the usefulness and meaning of intelligence testing continues within the field of psychology today, the greater practical problem is the general misconceptions of such testing by lay and legal communities. The Intelligence Quotient or "IQ" score that is produced by various tests is often misconstrued to be a measure of a how well a person's brain works, as well as their potential for learning in the future. "Mental age," a concept tied to IQ tests, is commonly misused to infer that people with ID/DD are incapable of developing beyond the abilities of young children. Originally, mental age, as determined by performance on the intelligence test, was used along with chronological age to calculate the IQ score. Although this concept is no longer used in most contemporary testing, it is still commonly used to explain the intelligence and abilities of people with ID/DD. For example, one family member explained that she was a guardian because "[o]ur daughter functions [as] a 5-year old to 16-year-old, depending on the context."

Properly used, intelligence and other tests can help practitioners understand individual learning challenges and make recommendations for improving educational and other learning support. In a 2003 article on "Intelligent Intelligence Testing," then president-elect of the American Psychological Association Diane Halpern noted that "We are not all the same; we have different skills and abilities. What's wrong is thinking of intelligence as a fixed, innate ability instead of something that develops in a context."[8] Science and experience have shown that human learning is a highly individualized process that can be facilitated by a variety of strategies and life experiences. While these interventions do not make a person's disability go away, they do function to strengthen other skills and help the person learn new ways to accomplish a challenging task.[9] This process is applicable to all areas of learning and life, including decision-making. It also means that not having the chance to learn to make decisions or taking away the opportunity and right to be involved in personal decision-making, preempts the person from becoming a better decision-maker over time.

Guardianship and People with ID/DD

Guardianship is a state legal process where a court removes some or many of the legal and decision-making rights from an individual and transfers all or some of them to another person, called a guardian or conservator. Although the particulars of guardianship depend on state law, an adult usually becomes subject to guardianship when a court, through a judge or magistrate judge, finds that the individual is incapable of making all

or some of their own financial or personal decisions and deems it necessary to appoint a guardian to make those choices on their behalf. The guardianship process usually starts with someone, such as a family member, a governmental agency, or a service provider, filing of a petition in the court with jurisdiction. The petition is generally followed by a notice of the petition to interested parties that a guardianship petition has been filed, appointment of an attorney to represent the allegedly incapacitated person, a capacity evaluation, court hearing(s), and, if the petition is successful, letters of guardianship. Once a guardianship is put in place, in most circumstances, it lasts either until the individual in guardianship dies or has their rights restored. Guardians' responsibilities under state law vary but may include submitting guardianship plans and initial and annual reports to the court.

The 2018 NCD report reviews this general process and fundamentals of guardianship in more detail, including what rights are at risk in guardianship, how courts determine incapacity, and what the scope of the guardian's authority may be.[10] Guardianships are typically separated into two categories: guardianships of the person and guardianships of the property (also sometimes referred to as *conservatorship*). When the guardian controls decisions regarding both person and property, the guardianship is called plenary or full. Some rights may be removed without being transferred to the guardian, such as the right to marry, vote, drive, or seek or retain employment. Other rights may be removed and transferred to the guardian to exercise on behalf of the person, such as the right to contract, sue and defend lawsuits, apply for governmental 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 person, 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.[11]

… [B]ecause of its legal implication on the person's civil rights, guardianship must be recognized as "an extraordinary intervention in a person's life and affairs," with the inherent potential to be a "drastic restraint on a person's liberty"…

In short, there are very wide-ranging actions that a guardian may be authorized to take on behalf of and instead of the person. This is why guardianship has been described as a "kind of civil death" for people subject to it, in that they are "no longer permitted to participate in society without mediation through the actions of another if at all."[12] Given the nature of our nation's existing legal system, there may well be times when guardianship is justified and necessary, although some disability rights advocates strongly disagree. Regardless, because of its legal implication on the person's civil rights, guardianship must be

recognized as "an extraordinary intervention in a person's life and affairs,"[13] with the inherent potential to be a "drastic restraint on a person's liberty,"[14] and, as such, an option of last resort. As emphasized in the 2018 NCD report, although guardianship is created by state law, it raises fundamental questions concerning federal civil rights and constitutional due process worthy of examination and intervention at the national level.

This impact of guardianship is particularly relevant to people with ID/DD, who have been found to be at increased risk for being made subject to it.[15] Guardianship is often implemented, because service providers, family, judges, and others assume people with ID/DD cannot make decisions for themselves,[16] despite research to the contrary.[17] As scholars have said, "rather than being treated as the extraordinary proceedings that they are, guardianships are often treated as a routine part of permanency planning for persons with [intellectual disabilities.] . . . [G]uardianships—including plenary guardianships—appear to be routinely granted over persons with [intellectual disabilities]."[18] This may be due to a combination of factors including the "School-to-Guardianship Pipeline" (discussed in Chapter 2), ID/DD specific guardianship statutes (discussed in Chapter 3), barriers to accessing alternatives, pressures by governmental and other agencies providing or funding disability-related services; and societal biases regarding ID/DD diagnosis and capacity. This project's stakeholder outreach indicated that these barriers may be overcame in individual situations, but societal misunderstandings of what it means to live with ID/DD persist. For example, a person with ID/DD told us: "People are shocked [I don't have a guardian] because I have so many disabilities and I have been told from people who did tests on me that I am like a 2 year old."

"[R]ather than being treated as the extraordinary proceedings that they are, guardianships are often treated as a routine part of permanency planning for persons with [intellectual disabilities.]"

Alternatives to Guardianship and People with ID/DD

As the American Association on Intellectual and Developmental Disabilities and The Arc of the United States have jointly concluded: "Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered."[19] Other common examples of legal alternatives to guardianship include health care surrogates by operation of state law, representative payees, trusts, and joint ownership. If alternatives to guardianship are thought of broadly—i.e., as services or supports that allow a person's needs to be met without a court-appointed guardian—many other options may be included within the continuum of decision-making support. These options include:

- voluntary participation in money management services
- case management services

- in-home care services
- food and prescription delivery
- daily call services
- direct deposit or bill pay
- medical or educational release forms to allow the sharing of confidential information with supporters
- other credit union and banking services technology [20]
- person-centered planning
- vocational services [21]
- supported living services.[22]

Emerging alternatives to guardianship in the United States include Physician Orders for Life-Sustaining Treatment (POLST) and, of particular relevance to people with ID/DD, ABLE accounts. The 2018 NCD report reviews at length the advantages and disadvantages of many of these less-restrictive options and includes discussion of the promising "PRACTICAL Tool," which was developed by the American Bar Association to encourage lawyers to identify and implement appropriate decision-making options for people with disabilities that are less restrictive than guardianship.[23]

For the purpose of the present report, NCD wants to emphasize that, from a rights perspective, alternatives that are voluntary in nature—i.e., decision-making support arrangements that are chosen and able to be cancelled or changed by the people with disabilities themselves—are less-restrictive than those that are involuntary in nature and, as such, are options that should be considered first for people with ID/DD. Voluntary alternatives to guardianship include tools such as supported decision-making (when people with disabilities use friends, family members, and others they trust to help them understand the everyday situations and choices they face, so that they can make their own decisions without the need for a substitute decision maker) and *powers of attorney* (written documents executed under state law that allows a person to voluntarily designate someone else to act for them in certain situations and to cancel or change that designation at a later time without court involvement).

[F]rom a rights perspective, alternatives that are voluntary in nature…are less-restrictive than those that are involuntary in nature and, as such, are options that should be considered first for people with ID/DD.

Involuntary alternatives involve some entity other than a court or the person with a disability appointing and having control over who serves as the decision-maker. They include options such as representative payees (which are appointed by SSA when it determines beneficiaries cannot manage or direct the management of his or her own benefits and cannot be independently removed or changed by the beneficiaries themselves), surrogate health care decision-makers (which are not acting under the authority of a power of attorney or judicial determination, but rather by operation of other state law, and usually involve some form of professional certification(s) of a person's incapacity to make health care decisions), and Educational

Representatives (which are discussed further in Chapter 2).

NCD supports delinking perceptions about the ability of people with ID/DD to access voluntary alternatives to guardianship from their diagnosis alone. Many people with cognitive and intellectual disabilities can knowingly and voluntarily execute powers of attorney or advance directives, yet misconceptions about this persist, [24] and opportunities to access these options may not be offered to them. A family respondent reported: "An attorney has claimed that our son does not have legal capacity to enter into a durable medical power of attorney due to . . . his intellectual disability, but he is very clearly expressing preferences and making decisions about what he wants in life."

NCD also cautions against the over-use of involuntary alternatives to guardianship for people with ID/DD. While they do not involve the court system and are expressly limited in nature, they are still a form of substitute or surrogate, rather than supported, decision-making.[25] For example, having representative payees is a common alternative to guardianship for people with ID/DD, based on the stakeholder respondents in this project. Yet, while there are benefits to having a representative payee in certain circumstances, there also risks to the beneficiary that should not be forgotten, including loss in their feelings of self-worth and autonomy, encouragement of dependence, stigmatization, and the possibility that the representative payee will financially exploit or use the benefits as leverage to control the beneficiary.[26] As the Social Security Advisory Board has recognized, "[t]he appointment of a payee represents the curtailment of certain rights for the beneficiary and, therefore, should be undertaken carefully" and with consideration of the supported decision-making (SDM) as an alternative to appointment.[27] A respondent agreed with such careful consideration: "I am considering terminating [my] role [as representative payee] in light of what I now know about supported decision-making. I would like to return the right to decide how his SSDI is spent to [my family member with ID/DD]. He is already more confident and assertive since the conservatorship termination, and I expect him to continue to grow as he takes ownership of his decisions with my support." Possible ways states can address concerns about other involuntary alternatives to guardianship, such as Surrogate Health Care Decision-Makers and Educational Representatives, are discussed in Chapter 5.

Finally, NCD sees SDM as an ever more promising and recognized option for people with ID/DD. Based on information from the National Resource Center for Supported Decision-Making's website, as of June 2018, of the almost 20 cases where a court terminated or denied a guardianship explicitly in favor of SDM, almost 90 percent of the cases involved people with ID/DD. The first reported court decision terminating a guardianship specifically in favor of SDM occurred in 2012 in the state of New York and was followed by other cases in New York (2015, 2016, 2017), Virginia (2013), Massachusetts (2015), the District of Columbia (2016), Florida (2016), Vermont (2017), Kentucky (2017), Nevada (2017), Maine (2018), and Indiana (2018).[28] Two of the people with ID/DD involved in such cases, namely Jenny Hatch of

Virginia[29] and Ryan King of the District of Columbia,[30] were highlighted in the 2018 NCD report as representative of the third wave of guardianship reform. Additionally, the first formal SDM pilot program in the United States involved people with ID/DD and was held in Massachusetts (2014-2016).[31] Since then, it has been joined by ID/DD-specific pilots in states such as New York (2016—2021),[32] Maine (2016-2017)[33], and Georgia (2018 and ongoing),[34] among others.

Supported decision-making also is beginning to receive public attention for people with ID/DD in the health care realm. For example, in a film called *Supported Decision-Making: Gabby's Story*,[35] a young woman with spina bifida describes her experience working with a health advocate through The Arc San Francisco. The film uses Gabby's story to illustrate the benefits of SDM, both as a decision-making approach and as a way of maintaining personal autonomy in managing one's own medical care.

Lacking a robust natural support system can be a barrier to some people's ability to use SDM. Gabby's story highlights the role organizations and community supports can play in advancing the decision-making rights of people with ID/DD. Under its Health Care Management Services program, which began in 2003, health advocates at The San Francisco Arc are available to assist people with ID/DD by attending medical appointments with them, helping them understand medical decisions, and acting as a facilitator between the supporter person and medical providers—all at no change to the people with ID/DD. According to Jennifer Dresden, the Director for the Center for Health and Wellness, the program empowers people with ID/DD to have control over their health care decisions and helps medical providers better understand and serve their patients. The National Disability Rights Network is also exploring the use of supported decision making in the healthcare context with support from a grant by the WITH Foundation.[36] This report will explore more promising practices to further promote self-determination throughout the life spans of people with ID/DD.

Chapter 2: School-to-Guardianship Pipeline for Youth with ID/DD

The School-to-Guardianship Phenomenon

The Individuals with Disabilities Education Act (IDEA) generally requires—once students in special education reach the age of majority (usually 18, depending on state law [37])— the school to transfer all of their parents' educational rights to them as part of the transition planning process.[38] When that occurs, students have the right to make their own educational decisions for as long as they are entitled to receive special education services—i.e., until they graduate from high school or exceed the maximum age for receiving special education services, which, in most states, is 21 years old. [39] However, under IDEA, the transfer of rights will not occur if the adult student is subject to guardianship. The transfer also will not occur if the school uses a separately established non-judicial educational representative process to determine that the student cannot provide informed consent to educational decisions and to appoint another person (usually a family member) as the adult student's educational representative. It is often at the transfer-of-rights juncture that many parents and school personnel question the competence of students with disabilities, and parents seek to become the legal guardian of their young adult children.[40]

However, under IDEA, the transfer of rights [to make one's own education decisions] will not occur if the adult student is subject to guardianship.

At this point in the IDEA transition process, guardianship can be set in motion by a variety of factors. First, intentionally or unintentionally, school professionals may be biasing parents toward pursuing guardianship because of the way in which they notify them of the transfer-of-rights process. For example, they may start the conversation by asking parents if they have guardianship or are planning to obtain guardianship, rather than discussing the student's strengths and abilities and less-restrictive options of decision-making support, such as SDM or educational powers of attorney.[41]

[S]chool professionals may be biasing parents toward pursuing guardianship because of the way in which they notify them of the transfer-of-rights process.

Additionally, school personnel might not be aware of alternatives to guardianship or its legal impact. As one former educator explained: "I recall hearing the Department Chair and others saying that, if the student does not have a guardian, then the parents cannot attend the meetings and it just makes things more challenging. [I was] not told about alternatives to guardianship." Such conversations may pressure parents to pursue guardianship over their adult child, so that they are assured they can continue to be involved in their child's education.

While IDEA does not require appointing a guardian for adult students in special education, it allows—and arguably mandates—states to establish alternative procedures, short of guardianship and consistent with state law, for the appointment of the parent or another person to represent the educational interests of an adult student, if the school district determines that the student is unable to provide informed consent to his or her education program.[42] Such extra-judicial processes raise due process concerns in that rights are being taken away from the student without court adjudication. They also promote substitute or surrogate decision-making—rather than SDM—in the educational context.[43] Based on a 2012 review of state law

Such extra-judicial processes raise due process concerns in that rights are being taken away from the student without court adjudication.

and regulations, at least six states had regulations that expressly provided for a non-judicial appointment of an educational representative for the student upon parental request and/or professional certification(s) or an Individualized Education Program (IEP) team finding that the student is incapable of providing informed consent for educational decisions. [44] The District of Columbia joined them in July 2016, as discussed in Chapter 5. Some states have other exceptions to the transfer of rights. In Maryland, for example, the general rule is that parents retain the special education rights of their adult child, unless they affirmatively or tacitly refuse or fail to participate in the special education decision-making process.[45]

There is no national data available on how many people with ID/DD get guardians right after high school. However, 2015-2016 National Core Indicator survey data indicates that the majority (58 percent) of people with ID/DD ages 18 to 22 receiving publicly funded services have guardians, which suggests guardianship is common for this age group. Moreover, as highlighted in the 2018 NCD report, stakeholders frequently reported that guardianship is presented by the school system as the main, if not only, option for decision-making support for young adults with ID/DD. A 2015 study supported by the TASH Human Rights Committee found that schools were the number one referral source for guardianship,[46] and guardianship is frequently considered the default option for students with ID/DD.[47] Many of the stories NCD collected affirm this.

[T]he majority (58 percent) of people with ID/DD ages 18 to 22 receiving publicly funded services have guardians …

A 2015 study supported by the TASH Human Rights Committee found that schools were the number one referral source for guardianship …

- A professional who used to work with transition-age youth in special education reported that she and her colleagues would give parents what was known as a "guardianship packet." She said: "It makes me cringe now, that that is how it was being passed around school, how nonchalant it is, and then how dangerous it can actually be . . . I didn't experience from my mentors that this was a human rights issue, that you were [contributing to] taking someone's rights away by recommending guardianship Parents see you as a representative and professional on behalf of the district, so if you say something like, '[H]ere is information on guardianship,' then they [may] not do their due diligence."
- As a Michigan family member reported: "Too often schools have told family members that a student with I[D]/DD must have guardianship if they want a family member or friend to assist with one's IEP when the student turns 18. School districts are terribly misinformed about guardianship and use this approach to limit families' involvement in IEPs."
- A Massachusetts family member reported: "People are encouraged by well-intended

educators to make the decision [about guardianship] at the age of majority. These educators do not connect the dots between transition when they should be teaching decision-making skills and the notion that guardianship is contrary to what they are supposed to be accomplishing."

- A person with ID/DD in Virginia said guardianship happens "at 18 because schools tell parents they have to have guardianship to make school and IEP decisions for and with their child, when people assume someone like me, who doesn't walk or talk, is stupid and needs to be put away and to make all the decisions about me for me."
- A family member from Kentucky said: "In my family's experience, we were prompted to begin the process [of obtaining guardianship] during his special education case conference meetings while he was still in high school. The school was not terribly helpful in informing us of the process, but did provide resources for where to go for more information."
- A Missouri family member reported: "It was recommended at my son's eighteenth birthday by the school officials that I file for guardianship."

Many stakeholders also referenced the lack of information on alternatives to guardianship provided by schools and its impact. For example: A family member reported: "Forms of limited guardianship were not discussed [in IEP team meetings], as it was assumed my brother [with ID/DD] would require plenary guardianship."

- A family member in Michigan responded: "Very, very little information [on this from schools]. Too often schools have told family members that a student with I[D]/DD must have a guardianship if they want a family member or friend to assist with one's IEP when the student turns eighteen. School districts are terribly misinformed about guardianship or use this approach to limit families' involvement in IEPs."
- A guardian in Missouri responded: "The educators do not support alternatives to guardianship."
- A lawyer in Indiana said: "There is no information available from the school. Our Protection and Advocacy organization has a website and will do information presentations."

Stories of the school-to-guardianship pipeline

A person with ID/DD in Virginia said guardianship happens "at 18 because schools tell parents they have to have guardianship to make school and IEP decisions for and with their child, when people assume someone like me, who doesn't walk or talk, is stupid and needs to be put away and to make all the decisions about me for me."

The Impact of the Pipeline and U.S. Policy Implications

Youth with ID/DD are ultimately disempowered by schools actively encouraging guardianship to the exclusion of less-restrictive alternatives, and not providing families and students in special education with sufficient information about the availability of a full continuum of decision-making supports. Research has found reduced self-determination can lead to diminished quality of life outcomes and reduced community integration and participation.[48] For young adults with ID/DD, guardianship may be an obstacle to the development of self-determination skills necessary for life after high school, such as critical thinking, self-advocacy, and knowledge of one's own skills, interests, strengths, and weaknesses.[49] Studies have found that students who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment, and independent living outcomes.[50] Studies also have found that the appointment of a guardian for a young adult with ID/DD did not necessarily resolve the areas of concern prompting it and, in some cases, the young adult under guardianship would have done just as well, if not better, without a guardian.[51] The guardianship often appeared to have benefited the guardian, rather than the person under guardianship.[52]

If states' educational systems are promoting guardianship without appropriate consideration of less restrictive alternatives, including supported decision-making, they are arguably violating the ADA …

For young adults with ID/DD, guardianship may be an obstacle to the development of self-determination skills necessary for life after high school …

The U.S. policy implications of the school-to-guardianship pipeline are also troubling. There are strong arguments to be made that it runs contrary to important civil rights laws impacting people with ID/DD. As the 2018 NCD report found, guardianship must be seen as subject to the Americans with Disabilities Act (ADA),[53] which has been interpreted by the U.S. Supreme Court in the 1999 *Olmstead* decision[54] to give rise to an obligation to provide services to people in the least restrictive environment that will meet their needs. If states' educational systems are promoting guardianship without appropriate consideration of less restrictive alternatives, including supported decision-making, they are arguably violating the ADA[55] and promoting outcomes that run contrary to the *Olmstead* community integration mandate. As one interviewee stated: "By definition, if you are not the person making decisions, your ability to be a real member of the community [is] smaller."

In addition, while there may be "traces of guardianship"[56] found within it, IDEA also mandates individualized transition planning for qualified students with disabilities to increase the likelihood of post-school employment and/or education.[57] Transition planning outcomes should be tailored to students and their individual preferences, needs, and strengths, so they should

contribute actively to the decision-making and planning process.[58] With that in mind, some scholars have suggested that "[t]he goals of transition planning, which focus on autonomy and independence, appear to be in direct conflict with the goal of guardianship, which is to facilitate the individual's dependence on another person's authority to make all or some of their decisions."[59] As one team of researchers observed, guardianship can work against the goals of transition planning, because it has broad implications regarding the loss of fundamental rights and personal liberty.[60]

"[t]he goals of transition planning, which focus on autonomy and independence, appear to be in direct conflict with the goal of guardianship, which is to facilitate the individual's dependence on another person's authority to make all or some of their decisions."

Moreover, the purpose of the federal Developmental Disabilities Assistance and Bill of Rights Act is to "assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life."[61] These goals are likely more readily achievable through alternatives that hold the promise of increasing self-determination, such as supported decision-making, rather than substitute decision-making. As one prior NCD interviewee stated: "[Guardianship is] never going to allow the person [subject to it] to really become integrated to [the] community because [others are] going to have to be always checking" with the guardian, not the person.

Finally, one of the goals of the Rehabilitation Act of 1973[62] is to promote and support employment for people with disabilities, including ID/DD. Its regulations have long recognized the importance of intervening early in the lives of transition-age youth with disabilities by mandating that state vocational rehabilitation programs coordinate with special education transition teams "as early as possible."[63] The Workforce Innovation and Opportunity Act (WIOA)[64] further augmented these requirements by mandating vocational programs to "provide pre-employment transition services to assist students with disabilities make the transition from secondary school to postsecondary education programs and competitive integrated implement" [65] In addition, Section 511 of WIOA was designed to make it less likely that youth who have disabilities and are age 24 or under are inappropriately routed to segregated, subminimum wage employment without first exploring all the alternatives for meaningful work and post-

[NCI] data indicates people with ID/DD who receive publicly funded services who are not under guardianship are more likely to be employed in an integrated job.

secondary education and training. Research has found young adults with disabilities who are supported have greater self-determination in their lives, are more likely to be better employed,[66] and National Core Indicator data indicates people with ID/DD who receive publicly funded services who are not under guardianship are more likely to be employed in an integrated job.[67] and those who are in guardianship are significantly less likely to have employment as a goal in their service plans.[68] Both of these findings suggests the Rehabilitation Act's and WIOA's goals may be better achieved by requiring schools and transition teams to ensure awareness of decision-making support options that do not remove the legal rights of young adults with disabilities.

It is therefore critical that the school-to-guardianship pipeline be dismantled so that students with disabilities and their families receive the information they need to make thoughtful and informed choices when it comes to guardianship and alternatives. As one former educator noted, too often, "students are not informed, parents are uninformed, and educators are uninformed . . . It's a triple whammy." Fortunately, efforts to address this information gap have been undertaken by the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS). In January 2017, OSERS issued its "Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities" report, which recognized the serious implications of guardianship and encouraged schools to recognize and promote supported decision-making and self-determination by students before, during, and after the age of majority. It also recognized other alternatives to guardianship in the educational context, including educational powers of attorney.[69] OSERS archived and then updated and reissued this guide, retaining these important elements of its guidance.[70]

However, based on the information received from respondents as part of this project, more is clearly needed to ensure that teachers, schools, and school districts are complying with this guidance. This should include:

- Revision of all teacher education and certification programs and vocational the full rehabilitation agencies to include training on range of decision-making options for students who have reached the age of majority. As one former educator said: "Being a first-year teacher shouldn't be the first time that I [am] learning about age of majority and guardianship [and alternatives] . . . [I]f the district itself is unaware or has varying views of student's abilities to lead independent lives, then you are at the mercy of the vision of the school.
  The universities [are in] a powerful position to prime the teachers."
- Training parents for school-to-adult transition and alternatives to guardianship. As one parent said: "When it comes to guardianship and alternatives, you don't know what you don't know."
- Promotion of self-advocacy and self-determination at an early age for students in special education. As one former educator said: "[Schools have] the power to promote

self-determination as early as possible and that can be done by empowering the students to lead the [IEP and other] meetings It puts them in a position of leadership and empowers them to take an active role. If the student has been passive throughout their entire education, maybe not even attending the meeting, how would the team even know if the student could make a choice if they are not even empowered in participating and attending the [very] meeting that is planning their education?

Chapter 3: Unequal Treatment of People with ID/DD Under State Guardianship Law

ID/DD-Specific State Guardianship Laws

Most states have a single guardianship law that covers people across disability categories, including older people with progressive cognitive decline, people with mental-health disabilities, and people with ID/DD. However, as recognized in the 2018 NCD report, there are states that have different statutory procedures, standards, and processes for appointing guardians for people with ID/DD, as compared to other populations that may need guardians. A list of these states and the main ways statutory distinctions apply to people with ID/DD is available in Appendix A of this report.

California, Connecticut, Idaho, Michigan, and New York… have separate guardianship statutes for people with ID/DD versus those with other types of disabilities.

Existing scholarship has mainly focused on the ID/DD distinctions in five states—California, Connecticut, Idaho, Michigan, and New York—which have separate guardianship statutes for people with ID/DD versus those with other types of disabilities.[71] On paper, New York's statute is one of the most striking. New York maintains two separate systems of guardianship for people with disabilities—i.e., Article 17-A of the Surrogate Court's Procedure Act for people with developmental disabilities and Article 81 of the Mental Health Hygiene Law for all other people. Under the former, the basis for appointing a guardian is driven by diagnosis, rather than functionality. It also has less rigorous procedural requirements than Article 18 of the Mental Health Hygiene Law—e.g., a hearing on the guardianship petition is not required; the person with a disability does not have to be present; the guardianship cannot be limited; and guardians' decisions are based on a "Best Interest," rather than a Substituted Judgment, standard. Additionally, unlike many other statutes, New York's statute allows a guardian appointed under it to make "any and all health care decisions" for the person with ID/DD.

On the other side of the spectrum is Michigan, which has a guardianship statute for people with developmental disabilities that generally provides them with more statutory safeguards than people without such disabilities. For example, the Michigan developmental-disability-specific guardianship statute requires that guardianships be limited in scope to only that which is necessary because of the person's actual mental and adaptive limitations. Partial guardianships are

preferred, but not required, and terminate after no more than five years.[72]

Apart from those states with entirely separate guardianship laws depending on a person's diagnosis, there are other states that make other kinds of distinctions for people with ID/DD, as indicated in Appendix A. For example, some allow for a governmental agency or representative to be appointed guardian of a person with ID/DD (e.g., Hawaii, Minnesota, and South Dakota), or others require additional court determinations (e.g., Iowa, with respect to voting rights) or clarify that an ID/DD diagnosis alone should not govern the scope of a guardianship (e.g., Arizona). As discussed in the 2018 NCD report, some states have so-called "alternatives to guardianship" that are essentially still guardianships. For example, Florida has a legal process for "guardian advocates" that is referred to in its statute as a less-restrictive alternative to guardianship and is only available to people with particular developmental disabilities. Rather than requiring Florida's standard determination of incapacity by an "examining committee" of experts, the judge (who may not have any expertise with disability) may use educational evaluations, IEPs, and other support plans to determine whether the person has the capacity to retain at least one right, but "needs" a guardian advocate appointed to exercise other rights. If so, that guardian advocate will essentially have the duties and responsibilities as a guardian under Florida law without the person having the same due process safeguards. [73]

Another example of the way in which some states relax due process protections for people with ID/DD—both expressly and indirectly—can be seen in Utah. Utah's law does not require a court visitor to investigate the appropriateness of appointing a guardian, if the person involved has an intellectual disability or an intelligence quotient score under 25—which, on its face, would appear to discriminate against people with certain ID/DDs. Additionally, in 2016, the Utah legislature passed a law that created an exception to a person's right to counsel when facing a guardianship petition. While not specifically referencing people with ID/DD, this law change made it easier for their parents to obtain guardianship over them and further bolstered the school-to-guardianship pipeline. The law was focused on the approximately 300 cases per year where parents seek guardianship over their adult children with disabilities in Utah state courts. [74] It eliminated the requirement that adults with disabilities have their own attorney when their parents petition the courts to be their legal guardians, their assets are less than $20,000, they appear in court with the petitioner, and they are "given the opportunity to communicate, to the extent possible, the person's acceptance of the appointment of petitioner." In July 2017, disability rights advocates filed legal action in federal court challenging the law on discrimination grounds. [75] In May 2018, the Utah Legislature amended this law to limit the applicability of the exception to the right to legal counsel and to require that, when it does apply, a court visitor, such as a social worker, be appointed to investigate and report to the court.[76] In November 2018, the federal court lawsuit was settled. As part of the settlement, the Utah Administrative Office of the Courts and the Utah Judicial Council agreed to strengthen legal protections for adults with disabilities in

guardianship proceedings by ensuring judges are informed about the importance and availability of legal representation in such proceedings, first explore less restrictive alternatives, and consider full guardianship as a last resort.[77] However, Utah's exception to the requirement of legal counsel in cases where parents are seeking guardianship over their adult children remains "on the books", albeit in a modified form.

The Impact for ID/DD Guardianship Statutes on People with ID/DD and U.S. Policy

Stakeholders in the affected states express varying knowledge and opinions of the impact different statutes have on people with ID/DD. One family member in Michigan, who serves as co-plenary guardian for her two sons with ID/DD, felt that the separate ID/DD law was a "good thing," because she saw "the problems with guardianship [as] varying a great deal for people who are elderly and people with [ID/DD]," since the former are more likely to have accumulated savings and property that can be exploited. Other Michigan stakeholders reported that the supposedly bolstered procedural safeguards of the ID/DD guardianship law were not playing out in practice. For example, the statute was designed to promote partial guardianships over plenary guardianships, with partial guardianships automatically expiring after five years. However, in some Michigan counties, stakeholders reported that partial guardianships for people with ID/DD are never ordered, while in other counties, so-called partial guardianships are so broad as to be, for all intents and purposes, plenary. One advocate described partial guardianship only preserving, for example, a person's right to choose their own clothing. This would seem to suggest that the manner in which guardianship plays out for people with ID/DD has little to do with how the actual law is written.

On the other hand, stakeholders in New York who commented on the different nature of the state's ID/DD guardianship statute raised serious concerns about its disparate impact, with one arguing that people with ID/DD deserved "equal protections under the law," and the other lauding a challenge to it on constitutional grounds. These concerns were forcefully brought to the fore in a 2015 report of the Mental Health Law Committee and the Disability Law Committee of the New York City Bar Association, which unequivocally concluded that the separate New York guardianship law "discriminates against persons with intellectual and developmental disabilities, denies procedural and substantive due process to those for whom guardianship is sought, and over whom guardianship is imposed, fails to honor or promote autonomy, self-determination and dignity, and fails to protect persons under guardianship from abuse, neglect and exploitation."[78] The New York Olmstead Cabinet made similar conclusions and recommended guardianship reform on the basis of the Americans with Disabilities Act, finding that "[c]ommunity integration includes the ability of people with disabilities to make their own choices to the

[T]he manner in which guardianship plays out for people with ID/DD has little to do with how the actual law is written.

maximum extent possible," and that guardianship "should, consistent with *Olmstead* only be imposed if necessary and in the least restrictive manner."[79]

Separate statutory guardianship schemes also may raise questions that are relevant to NCD's upcoming report series on bioethics and disabilities. One of the more pertinent questions with respect to bioethics is whether the separate guardianship schemes for people with ID/DD will protect the right of people with ID/DD to make important decisions about their health to the same extent as people covered by non-disability specific guardianship statutes. Many modern guardianship statutes prohibit the guardian from consenting on behalf of the person under guardianship to certain drastic medical procedures, such as removal of an organ or commitment of the person to a nursing facility or institution.[80] However, only some of the ID/DD-specific statutes prohibit guardians appointed under the subsection from making health care decisions that could permanently alter the health of the person under guardianship. For example, as noted in Appendix A, Connecticut's ID/DD-specific statute prohibits both plenary and limited guardians from "removing a bodily organ," except in accordance with statutory procedures to save the person's life or protect the person's physical or mental health. New York's statute, by contrast, allows the guardian to make "any and all health care decisions" for the person with a disability if it is in the person's best interests, which would include an organ transplantation or removal. New York's highly permissive statute would appear to raise significant concerns as to whether the bodily integrity of persons under guardianship under its provisions is truly respected.

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Whether or not a state's disability-specific guardianship statute does, in fact, make it easier to obtain guardianship over a person with ID/DD, the fact that some state law has different guardianship standards that apply to this population is concerning, since it still links the removal and transfer of rights to a person's diagnosis. If, as a nation, we are to move away from a diagnosis and medically driven system for guardianship toward the functionally driven approach that recognizes less-restrictive options for all people with disabilities, we need to encourage a more uniform state approach, as endorsed by the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act[81] and the 2018 NCD report.[82]

One of the more pertinent questions … is whether the separate guardianship schemes for people with ID/DD will protect the right of people with ID/DD to make important decisions about their health to the same extent as people covered by non-disability specific guardianship statutes.

Chapter 4: U.S. Trends in Guardianship/Alternatives and People with ID/DD

The Guardianship Data Problem

The 2018 NCD report recognized that national and state data on guardianship itself—let alone the demographics and type of disabilities of people subject to it—are scant to non-existent. Even identifying the number of active cases or their status is not possible in many states.[83] Record keeping is frequently inconsistent or dated, and most states do not have centralized data collection or tracking systems. The 2018 NCD report recommended that Congress and the Administration develop initiatives to produce effective and comprehensive data on guardianship. As one scholar said: "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 guardianship in the state courts." [84] In short, we collect data on issues that are important to us. Guardianship should be one of those issues, given its impact on the civil rights of people with disabilities and the potential impact on their ability to live, work, and participate in the community.

"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 guardianship in the state courts."

This project adopted a two-pronged approach to identify data-supported trends in guardianship and alternatives specific to people with ID/DD. First, it turned to National Core Indicator (NCI) data publicly available through the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) NCI initiative. This data is the result of surveys across the nation of people with ID/DD who receive publicly funded services through the state and includes information about guardianship and life outcome measures. The results of that NCD's examination are summarized in this chapter and Appendix B and C. Second, this project conducted a "deep dive" analysis of guardianship's impact on people with ID/DD within the District of Columbia, the nation's capital, including identifying and analyzing ID/DD specific data points that are not yet publicly available in other jurisdictions. The results of that analysis are summarized in Chapter 5.

Review of National NCI Data

National Core Indicators (NCI) (https://www.nationalcoreindicators.org/) are standard measures to assess the outcomes of services provided by public developmental disabilities agencies to adults with ID/DD. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety. Using the NCI website developed by HSRI and NASDDS, users can generate charts related to specific outcome measures with NCI data from the years 2008-09 through 2015-16. Most importantly for the purpose of this report, the NCI Chart Generator can filter data by whether the person has a legal guardian or not. Users can also filter results by race, ethnicity, gender, age, and type of residence, among other key demographics. While not comprehensive of all persons with ID/DD in the United States, the NCI data is one of the only sources of nationwide data on people with ID/DD and guardianship.

NCD used the NCI Chart Generator to review relevant data from 2008-09 to 2015-16. We also reviewed the NCI In-Person Survey National Reports for 2016-17 and 2017-18, which were published by HSRI and NASDDDS in May 2018 and March 2019, respectively, and included NCI data points that are not available for filtering through the NCI Chart Generator. NCD's review of this data by state is set forth in Appendix B as a table, which includes the percentage of people with ID/DD in guardianship (limited, full or the scope of which was undetermined) and the NCI Average by year from 2008 to 2018. While the District of Columbia and all U.S. states except Iowa, Montana, North Dakota, and West Virginia have participated in the NCI initiative, Alaska, Idaho, and Nebraska did not have guardianship-specific data available through the NCI Chart Generator. Relevant information relating to the state percentage of guardianships was available for Idaho in the 2016-17 NCI In-Person Survey National Report and for Nebraska in the 2016-17 and 2017-18 NCI In-Person Survey National Reports.

As reflected in Appendix B, trending of NCI data sheds light on the prevalence of guardianship across participating states:

- The reported percentage of people with ID/DD in guardianship (full, limited, or of undetermined scope) varies widely between states. In 2017-18, the highest were Nebraska (89 percent), Connecticut (84 percent), Missouri (82 percent), Michigan (81 percent), and North Carolina (75 percent), and the lowest were Delaware (5 percent), South Carolina (9 percent), Georgia (16 percent), Louisiana (16 percent), and Pennsylvania (18 percent). In 2017-18, most people with ID/DD surveyed in 20 of the 36 participating jurisdictions included in the 2017-18 NCI In-Person Survey National Report that year had guardians.
- The overall average of state percentages of people with ID/DD in some form of guardianship has ranged between 45 and 55 percent annually across the ten years of NCI data reviewed. The NCI Averages of cases of guardianship across participating states ranged between 43 and 53 percent annually during that ten year time period. Of the 17 states that have NCI data available from both

the 2008-09 and 2017-18 reporting periods, most had guardianship percentage increases, some of which were relatively small – i.e., Alabama (1 percent), South Carolina (2 percent), Ohio (6 percent), Pennsylvania (6 percent) – and others that were more significant – i.e., New York (10 percent), Wyoming (11 percent), Arkansas (12 percent), North Carolina (12 percent), Connecticut (14 percent), and Indiana (19 percent). Three states – Louisiana, Missouri, and Oklahoma – had no change in the percentage of people with ID/DD in guardianships in 2008-09 compared to the percentage in 2017-18. Five states had decreases in the percentage of people with ID/DD in guardianship, four of which were relatively modest – i.e., Massachusetts (minus 2 percent), Georgia (minus 5 percent), Kentucky (minus 8 percent) and Illinois (minus 8 percent). Based solely on those two-years-worth of NCI data, Delaware had the most significant decrease – minus 24 percent.

- Based on the individual states' averages, when a person is in guardianship, most are full guardianships. Only California and the District of Columbia regularly had more limited guardianships than full guardianships. However, that trend changed for the District of Columbia in the years 2016-17 and 2017-18, when the percentage of full guardianships became slightly higher than limited ones.

Percentage of people with ID/DD in limited or full guardianship

In 2015-16, the highest percentages of people with ID/DD in limited or full guardianship were:

- Connecticut (83 percent)
- Missouri (80 percent),
- Maine (77 percent)
- Vermont (77 percent)

and the lowest percentages of people with ID/DD in limited or full guardianship were:

- Louisiana (13 percent)
- Georgia (16 percent)
- Pennsylvania (18 percent)

In terms of the five states that apply entirely separate guardianship statutes to people with ID/DD, two were well under the overall state average percentage of 49 percent—namely California (overall annual average of 23 percent) and New York (overall annual average of 32 percent). The other three—namely Idaho (overall annual average of 58 percent) Michigan (overall annual average of 76 percent) and Connecticut (overall annual mean of 80 percent) were well above that overall state average. This suggests that whether a person with ID/DD is under guardianship may have very little to do with the type of guardianship law that is applied to them.

Appendix C tabulates additional NCI guardianship data by gender, and race/ethnicity and was developed by NCD through the use of the NCI Chart Generator, which is currently limited to data from 2008-09 through 2015-16. NCD's review of that data indicates that here is no significant

difference between the percentage of male and female participants who have guardians (annual average 48 percent versus 49 percent), but the percentage of people with ID/DD who have guardians was highly variable by race and ethnicity. There is no significant difference between the percentage of male and female participants who have guardians (annual average 48 percent versus 49 percent), but the percentage of people with ID/DD who have guardians was highly variable by race and ethnicity.

[T]he percentage of people with ID/DD who have guardians was highly variable by race and ethnicity.

After this report was nearly completed in April 2019, NASDDDS and HSRI, in partnership with the University of Missouri, Kansas City, released a report, "What Do NCI Data Reveal About the Guardianship Status of People with IDD?" ("NASDDDS/HSRI/UMKC Report").[85] This report included an analysis of new data from the NCI 2017-18 In-Person Survey National Report, which was published in March 2019 and includes data not currently available through the public NCI Chart Generator, and raised resulting policy questions, as well as promising practices. Among other findings, the NASDDDS/HSRI/UMKC report analyzed the demographics of people with ID/DD surveyed, based on their guardianship status. Findings trended by race included:

- People with ID/DD surveyed who are White were significantly more likely to be in guardianship (46.4%) than people who were Black (34.2%) or Hispanic (26.3%).
- People with ID/DD surveyed who are Black and have a guardian were significantly more likely to have a public guardian or public administrator as a guardian (18.4%) than people who are White (11.2%) or Hispanic (4.3%).
- People with ID/DD surveyed who are Hispanic were significantly more likely to have a family member as guardian (91.1%) than people who are Black (71.6% or White (81.6%).[86]

Appendix C also has additional NCI guardianship data by age. For example, from 2008-16, roughly 50 percent of people with ID/DD between ages 18-74 had guardians, and this did not vary much between 18- to 34-year-olds (50 percent), 35- to 54-year-olds (48 percent), and 55- to 74-year-olds (48 percent). Based on the annual average, people with ID/DD who are 75 years or older were more likely not to have a guardian (71 percent). For its 2015-16 data collection, the NCI initiative broke down the 18- to 34-year-old category into two subcategories—18- to 22-year-olds and 23- to 34-year-olds. Based on the 2015-16 NCI average, 18- to 22-year-olds were the most likely of all the age groups that year to be in guardianship (58 percent). In addition, the 2015-16 NCI average percentage of people with ID/DD

Based on the new 2015-16 NCI Average, 18- to 22-year-olds were the most likely of all the age groups that year to be in guardianship (58 percent).

75 years or older without guardianship (52 percent) was notably lower than the 2008-15 NCI average (71 percent).

NCI data, however, does not necessarily provide a complete picture of guardianship for people with ID/DD in all the participating states. For example, based solely on NCI data, Missouri has consistently been the state with one of the highest percentage of people with ID/DD under guardianships (ranging from 80 percent in 2015-16 and 2016-17 to 87 percent in 2009-10 and 2013-14). However, each state participating in the NCI initiative decides what population of people with ID/DD it surveys, and most do not survey all people with ID/DD in the state. According to stakeholder interviews, Missouri conducted NCI surveys of people with ID/DD receiving Individualized Supported Living and Residential Services. Therefore, if some people with ID/DD in Missouri receive different services (such as individual supports, self-direction services, or employment services) or no services, they would not be included as part of the NCI data set. To obtain a clearer picture of guardianship data, in September 2018, the Missouri Department of Mental Health's Division of Developmental Disabilities conducted an initial data analysis of all its Medicaid HCBS Developmental Disabilities Waivers, except for autism services. It determined that the percentage of people with ID/DD served under these waivers who had guardians and/or conservators was approximately 50 percent—which is much lower than indicated by NCI data.

In addition, some states may have existing NCI data relevant to guardianship that is not within the NCI Chart Generator or the In-Person Survey National Reports. For example, Alaska was one of the states for which guardianship-specific data is not included in either of those resources. However,the 2015-16 Alaska NCI Adult Family Survey Final report indicatesthat 100% of the the family members with ID/DD are under limited or full guardianship, and 96% of these individuals are under full guardianship. [87] Based on stakeholder interviews, that startling statistic is far above that of any of the states listed in Appendix B and reportedly led local advocates to push for legislation, making Alaska the first state to allow people with guardians to execute SDM Agreements with the permission of their guardians. [88] The reported reasoning was that Alaska should not leave such a large percentage of people with ID/DD behind in its reform efforts to recognize and promote decesion-making rights. In addition, SDM agreements of this kind may serve as a gateway for people to work with their guardians toward rights restoration and greater independence.

NCI data, however, does not always provide a complete picture of guardianship … [E]ach state participating in the NCI initiative decides what population of people with ID/DD it surveys, and most do not survey all people with ID/DD in the state.

Even with the acknowledgment of its limitations, NCI data can provide indicia of the possible impact of guardianship in the lives of people with ID/DD. For example, the NASDDDS/HSRI/UMKC Report

analyzed outcomes for people with ID/DD with and without guardians, based on the most recent 2017-18 NCI data. The report found that NCI respondents without guardians are less likely to live in their own homes or apartments, be included in the community, have their rights respected, have community jobs or service plans with that goal, be supported to communicate with friends, go on dates or marry, and be involved in making choices about their own lives (e.g., where and with whom to live, who their support staff or case managers are, what their schedule looks like, what to do during their free time or during the day, and what to buy with spending money. [89]

NCI data also can be used to explore whether or not people with ID/DD who have guardians are more or less likely to live in restrictive environments than those who do not. Scholars have disagreed as to whether people with guardians are predisposed or disproportionately subject to institutionalization. Some argue that they are,[90] pointing to studies done of residential decisions made by a sample of state public guardianship programs.[91] Others disagree,[92] citing studies indicating that guardianship may delay institutionalization, although ultimately not prevent it. NCI data indicates that the answer to this question may be more nuanced for people with ID/DD. In the NASDDDS/HSRI/UMKC Report, the most recent 2017-18 NCI data indicated that NCI respondents in guardianship were significantly more likely to live in group residential facilities and less likely to live in their own home/apartment.[93] However, that report also found that respondents in guardianship were not more or less likely to live in an ICF/IDD, nursing facility, or other institutional setting than those who were not under guardianship.[94] -- which is contrary what NCD found within older 2015-16 NCI data (see Table 6 of Appendix C).

[A]ny NCI data correlation between guardianship and institutionalization does not get to the core question of whether it is guardianship itself that led to the person living in a more restrictive residential environment.

Ultimately, any NCI data correlation between guardianship and institutionalization does not get to the core question of whether it is guardianship itself that led to the person living in a more restrictive residential environment. The answer is more complicated than that and likely dependent on other factors such as whether a state's service delivery systems or supports appropriately promotes community living for people with disabilities.

Chapter 5: Guardianship & People with ID/DD: A Story from the Nation's Capital

Introduction

Who is filing guardianship petitions over people with ID/DD? Are suspicions of a "school-to-guardianship" pipeline for people with ID/DD borne out in actual guardianship data? Do people with ID/DD in guardianship ever seek to have their rights restored? Data-supported answers to these and other more granular questions impacting people with ID/DD are not available for the United States as a whole. Therefore, this project turned to the local level by undertaking an in-depth examination and analysis of the experience of people with ID/DD who live in Washington, DC.

The District of Columbia is a prime place for such an examination. The treatment of the decision-making rights of DC citizens with ID/DD has recently been highlighted on the national stage. During recent U.S. Supreme Court justice confirmation hearings, repeated references were made to a 2007 U.S. Circuit Court for the District of Columbia decision, *Doe ex rel. Tarlow*.[95] This court decision was condemned by several disability rights organizations[96] for not respecting the wishes of all of DC's citizens with ID/DD with respect to their own medical care. In addition, this case highlights the way in which the DC government used to consent to elective surgeries, including abortions, for certain DC citizens with ID/DD without attempting to ascertain their wishes. Since that time, DC laws and governmental practice impacting the decision-making rights of people with ID/DD improved in significant ways. However, that concerning history remains in the minds of many local advocates and DC residents with ID/DD. As one DC advocate with ID/DD said with respect to the *Doe* decision: "Nothing about us without us."[97]

In addition, from a data gathering standpoint, identifying and tabulating guardianship cases that specifically involve people with ID/DD, rather than other disabilities, is easier in DC than in other larger jurisdictions, because DC has only one court branch with authority over guardianship matters. DC also has a computerized system, with court filings and other information publicly available for review. In addition, the DC Department on Disabilities Services is legislatively required to gather information on decision-making supports used by the people with intellectual disabilities[98] that it serves. DC also has recently undergone promising legislative and policy reform, designed both to bolster due process rights for people facing or in guardianship and to promote alternatives to guardianship for adults with disabilities in special education and beyond. This presented an opportunity to find out whether these reforms have yet resulted in meaningful

outcomes for residents with ID/DD in the nation's capital, and, if so, whether DC's local approach can inform federal-level policy recommendations and serve as a model to other states.

Why NCD picked DC for an in-depth examination of guardianship

- DC has only one court branch with authority over guardianship matters, making it easier to identify and tabulate cases that specifically involve people with ID/DD.
- DC has a computerized system with court filings and other information publicly available for review.
- The DC Department on Disabilities Services is required to gather information on decision-making supports used by the people with ID that it serves.
- DC recently underwent promising reform designed to bolster due process rights for people facing or in guardianship and to promote alternatives to guardianship.

Key DC Legislative and Policy Reform

Legislative Reforms for Adult Guardianship Proceedings

In its guardianship law, DC has several long-standing safeguards and due process protections. For example, people facing or in guardianship have an established right to counsel, both in the initial and post-appointment court proceedings, such as restoration cases.[99] Even if a person is found by the court to be "incapacitated," a guardian may not be appointed unless it is "necessary as a means for providing continuing care and supervision of the person," which allows for court consideration of less-restrictive alternatives to guardianship. The law also states that incapacity must not be inferred from the fact that a person has an intellectual disability.[100] The law further provides for scope-limited and time-limited guardianships and requires the court to "exercise [its] authority … so as to encourage the development of maximum self-reliance and independence of the incapacitated person."[101] When the court appoints a guardian, it must be "the type of guardianship that is least restrictive to the incapacitated individual in duration and scope, taking into account the [person's] current mental and adaptive limitations, the [person's] ability to improve his or her condition, or other conditions warranting the appointment."[102] General and limited guardians are generally required to make decisions for the person using the substituted judgment standard[103] and to include the person "in the decision-making process to the maximum extent of the [person's] ability" and "encourage the [person] to act on his or her own behalf whenever he or she is able to do so, and to develop or regain capacity to make decisions in those areas in which he or she is in need of decision-making assistance, to the maximum extent possible."[104]

The [DC] law also states that incapacity must not be inferred from the fact that a person has an intellectual disability.

However, local disability rights advocates have raised concerns regarding how the due process protections within the DC guardianship law have been translated in practice for residents with disabilities.[105] Related advocacy led to the DC Guardianship Amendment Act of 2014,[106] which went into effect in March 2015. In addition to other reforms, it bolstered the due process rights

of people in guardianship proceedings in two main ways. First, the Act requires attorneys who represent people in or facing guardianship to zealously advocate for their client's expressed wishes. If the person is completely incapable of expressing such wishes concerning guardianship, then the attorney must advocate for a result that is least restrictive of the person's liberty and consistent with the person's interests as determined by a guardian ad litem.[107] This amendment was designed to counteract a 2010 DC Court of Appeals decision, *In re Martel,*[108] which held that the original guardianship statute's wording allowed an attorney to meet his or her obligation by advocating for what a guardian ad litem determined was in the person's "legitimate interests," even if the client disagreed. Second, the Act mandated periodic court review of guardianships established after January 1, 2015, to determine whether the guardianship continue to be the least restrictive option or whether it should instead be modified or terminated.[109] The reviews occur every three years, after an investigation and report by a case reviewer, who is a social worker assigned through DC's Guardianship Assistance Program. That investigation must include an updated medical or psychological information about the current capacity of the person in guardianship, as well as the person's expressed preferences about the scope and duration of the guardianship and their opinion of the guardian. The law also requires a court hearing to be held if the person in guardianship requests one or if the case reviewer recommends the guardianship be modified or terminated or the guardian be removed.

DC WINGS Complaint Process and Trainings on Alternatives to Guardianship

In 2015 and 2016, as a result of the efforts of the DC Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) initiative,[110] led by the DC Courts, other steps were taken to improve the guardianship system in DC. In addition to its efforts to improve public education on guardianship through the court website, brochures, and videos, DC WINGS developed a new complaint process, by which anyone can raise concerns about guardians and conservators that are appointed with the court. When such a complaint is submitted, the Court may take several actions, including appointing a social worker to investigate the case, referring the case for mediation, holding a hearing, or referring the complaint to a law enforcement agency,[111] among others.

DC WINGS developed a new complaint process, by which anyone can raise concerns about guardians and conservators that are appointed with the court.

In the fall of 2015, DC WINGS also provided training to attorneys and other legal stakeholders to reinforce that guardianship was the option of last resort, ensure alternatives to guardianship were understood, and improve understanding of capacity assessments. The trainings included discussion of the full range of decision-making options then available in DC, including SDM, advance directives, powers of attorney, representative payees, and substitute health care decision-makers under DC Code 21-2210 ("21-2210 Medical Decision-Makers"), among others.

DC Special Education Reforms to Promote Alternatives to Guardianship

In DC, while general education students typically graduate from high school by the age of 18, students in special education have the right to remain in school until the end of the semester in which they turn 22 years old.112 Under DC law, when students turn 18, their parents' rights under the Individuals with Disabilities Education Act (IDEA) automatically transfer to the student, unless a court has found that the adult student is incompetent.[113] This process is referred to as the "transfer of rights," and it frequently triggers discussions about guardianship. As one DC disability rights advocate said: "In my experience working with transition-age students with ID/DD, I have seen a bias by schools and support teams to use the transfer-of-rights process to push parents towards going to court to get guardianship over their adult child, rather than first exploring less-restrictive decision-making options, like powers of attorney and supported decision-making. Because of this institutional bias within [the] disability service delivery system, we have had to expend much effort and energy on counseling and supporting families to understand that guardianship is not the only option available."

In 2012, a coalition of DC disability rights advocates issued a call of action against the Transfer of Rights Guidelines of the DC Public Schools (DCPS).[114] These March 2010 guidelines failed to inform parents and students about less-restrictive alternatives to guardianship, such as educational powers of attorney or SDM, instead presenting the issue as a dichotomous choice between the students exercising their IDEA rights completely by themselves or their parents seeking guardianship if they wanted to remain involved in educational planning.[115] In addition, DCPS was taking the position at some administrative hearings that students in special education could not delegate their IDEA rights to their parents or caregivers through the use of educational powers of attorney, despite the fact that District law expressly allowed parents to delegate rights and responsibilities for all school-related matters when their child was a minor.[116] As a result of this community advocacy effort, in August 2013, DCPS amended its Transfer of Rights Guidelines[117] to expressly recognize SDM and, also developed a standardized form[118] by which such arrangements by adult students in special education can be documented. In addition, DCPS began an initiative to introduce SDM, beginning in pre-kindergarten, to teach "students how to build networks of support early to ensure that [they] are familiar with the process and utilize it in day-to-day activities."[119]

DCPS began an initiative to introduce SDM, beginning in pre-kindergarten, to teach "students how to build networks of support early to ensure that [they] are familiar with the process and utilize it in day-to-day activities."

Alternatives to guardianship for adult special education students were also included in comprehensive special education reform legislation that was passed by the DC legislature in late 2014. The DC Special Education Student Rights Act of 2014,[120] which went into effect in March 2015,

affirmed that students who have reached the age of 18 have the right to receive support from another adult to aid them in their decision-making.[121] In so doing, it extended DCPS' formal recognition of SDM to all schools in DC, including public charter schools. The Act also affirmed the right of adult students in special education to execute educational powers of attorney[122] and required the DC Office of the State Superintendent of Education (OSSE) to create a new alternative to guardianship for students who were unable to make educational decisions—even with support—or to knowingly and voluntarily execute a power of attorney.[123] This new alternative became known as an Educational Representative. The Act also required parents be notified of the transfer-of-rights, as well as all these alternatives to guardianship, no less than one year before the student turned 18 years old.[124]

In July 2016, OSSE implemented regulations for this Act[125] and issued a model SDM form that can be used by all schools, whether they are connected to DCPS or not.[126] Among other things, the regulations describe how the Educational Representative process works. An Educational Representative is someone, usually a parent, appointed by OSSE to make educational decisions for an adult student who is unable to make those decisions, even with support, and it does not require court involvement. A parent or other interested adult may submit to OSSE the request for appointment, along with two signed professional certifications of the student's incapacity to make educational decisions. If all its rules are met, OSSE will then appoint the Educational Representative and provide notice of the appointment to the parents, student, and school. The notice describes the steps that the student may take to challenge the appointment; and the school is required to give a copy of the notice and explain it to the student. If the student objects, then the certifications are invalidated, and all educational rights transfer back to the student.[127]

However, respondents that were interviewed raised questions about whether information about the full continuum of decision-making support are really making its way from schools to students and families. For example, one parent reported that, coordinators at public charter schools and DCPS do not have a full understanding of the impact of guardianship or the availability of alternatives such as powers of attorney and SDM: "Maybe a handful out of the 200 or so that are out there [do] . . . We really do need to get [them] . . . much, much more comfortable in explaining the difference or at least pointing parents in the right direction [when students are] 15, 16 . . . in their IEP [meetings]. I think they really need to ramp up the trainings .I know it's a very low-priority level, unfortunately, but I think that they are the ones who are going to open the door of understanding to the parents."

Reforms Recognizing Supported Decision-Making Across the Life Span

On September 21, 2015, the Chairman of the DC Council, at the request of the DC Mayor, introduced Bill 21-0385, the Citizens with Intellectual Disabilities Civil Rights Restoration Act of 2015. This bill, among other things, proposed to formally recognize SDM across the life span through the codification of a SDM agreement form and was drafted under the leadership of the DC Department on Disability Services. Although it did

not pass the DC Council that legislative session, the introduction of Bill 21-0385 started a broader dialogue about SDM that made lawmakers, governmental agencies, and the public more familiar with the concept and how it could be operationalized in DC. The legislation was reintroduced on March 3, 2017, in a modified form, as Bill 22-0154, now known as the "Disability Services Reform Amendment Act of 2018." It passed the DC Council on February 28, 2018, and became law effective May 5, 2018, making DC the fourth jurisdiction in the United States to codify SDM agreements.[128]

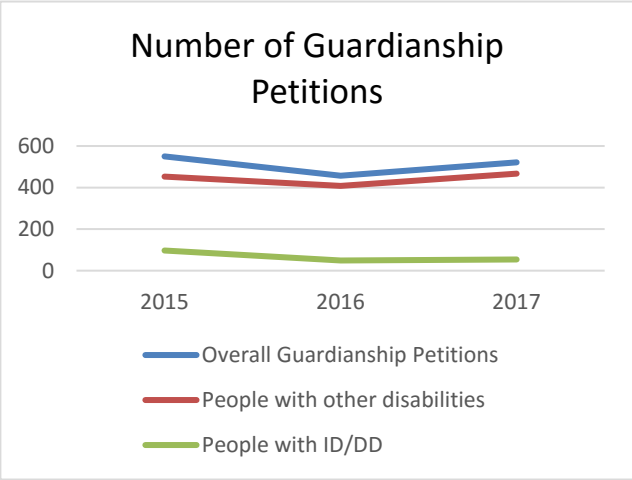
This law change was preceded in October 2016 by the first DC case to terminate a guardianship in favor of SDM.

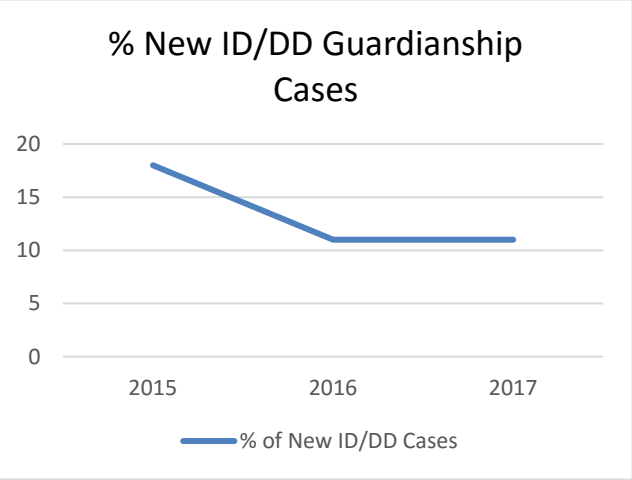
This law change was preceded in October 2016 by the first DC case to terminate a guardianship in favor of SDM.[129] The case involved Ryan King, a person with ID/DD whose victory was showcased in the 2018 NCD report and shown a spotlight on SDM locally and nationally. In addition, DC's 2016 Olmstead Plan—which is a way for states to document their plans to provide services to people with disabilities in the inclusive and integrated settings, pursuant to the Americans with Disabilities Act (ADA)—recognized that: "Guardianship is often seen as the only option for parents of children with disabilities rather than self-determination and supported decision-making." To combat this, it included governmental action steps that required the development and implementation of long-term care competency criteria, standards, policies, and protocols on the "consistent use of person-centered approaches to service and planning, including using principles of supported decision-making."[130]

By the Numbers: Guardianship and DC Residents with ID/DD

Data Collection Initiative at the DC Probate Branch

Using publicly available information from the DC Probate Branch, this project gathered key data points for the over 1,500 new guardianship cases opened over the course of 2015-17 and identified the subset of cases where the alleged disability was ID/DD. There are several trends that are worth highlighting.





The number of new guardianship petitions for people with ID/DD, as well as their percentage compared to overall guardianship petitions filed, has generally decreased over the course of the three-year period. While there are many reasons why this is the case, the timing of the decrease coincides with the public dialogue surrounding the SDM bill that was first introduced in the DC legislature in 2015, as well as the DC WINGS trainings on alternatives to guardianship. Most of the petitions were filed by family members. Others were submitted by government agencies, including Adult Protective Services (APS), the Department on Disability Services, and Child and Family Services. In a handful of cases, the person's own attorney or guardian ad litem from another matter, such as an eviction proceeding, filed the petition. The overall percentage of family guardianship petition filings increased over the three-year period, which speaks to a need for targeted outreach to that population to ensure they are fully aware of less-restrictive options.

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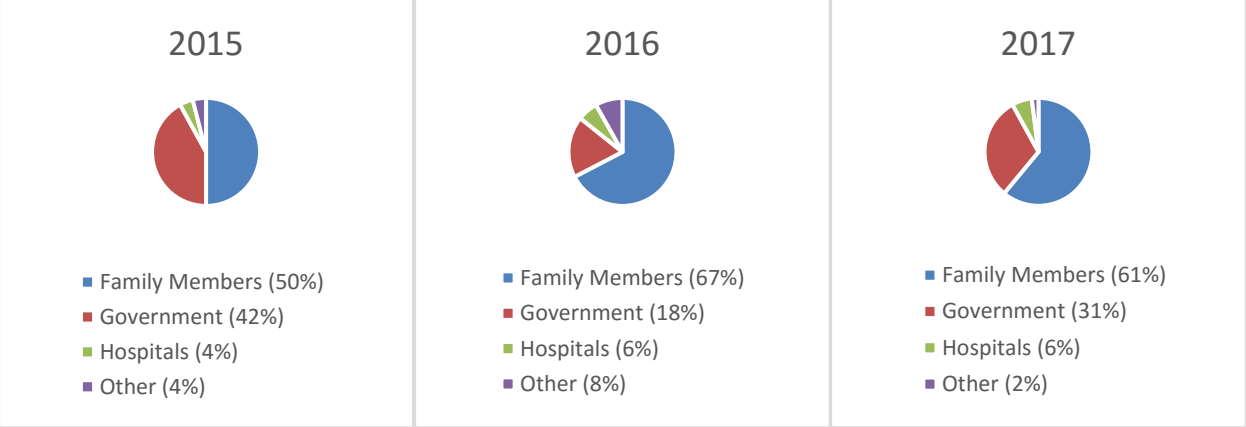
Guardianship Petitioners for ID/DD Cases



The majority of ID/DD guardianship petitions are for transition-age adults, indicating that there is indeed some form of pipeline to guardianship for that population in DC. While the number of cases for that age group has dropped since 2015, their percentage of the overall number of guardianship petitions involving people with ID/DD has steadily increased. This is a troubling finding, as it suggests that the special education reforms to promote alternatives to guardianship may not yet be having an impact on the ground for youth with ID/DD.

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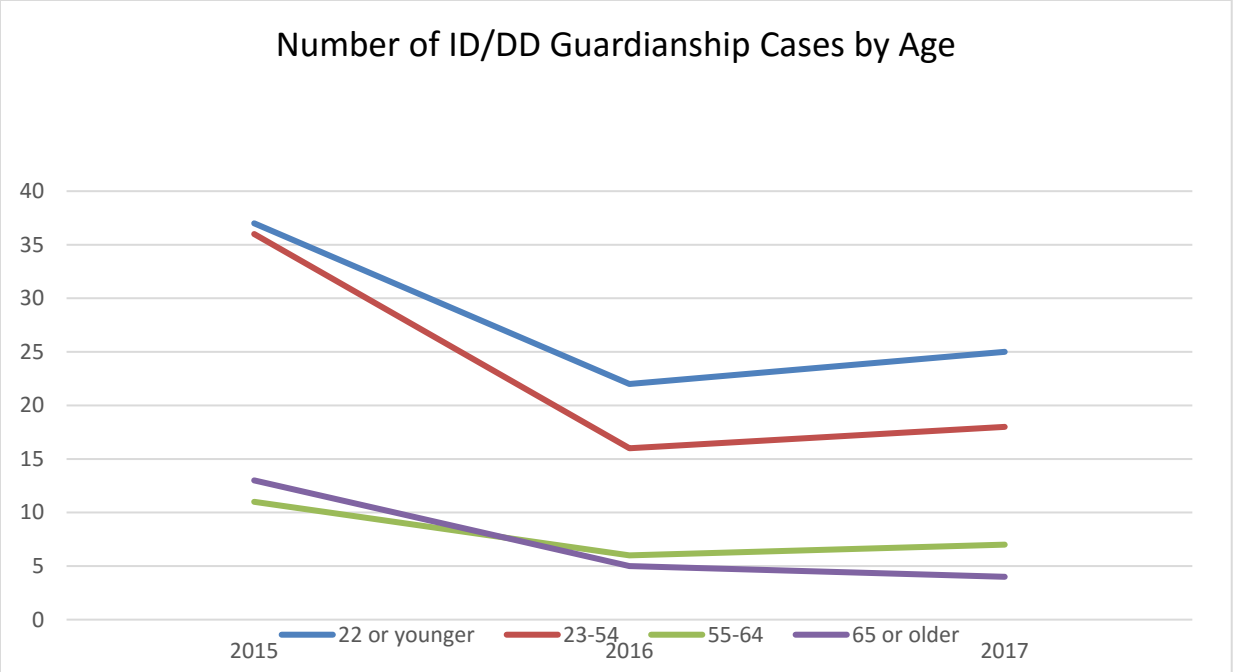
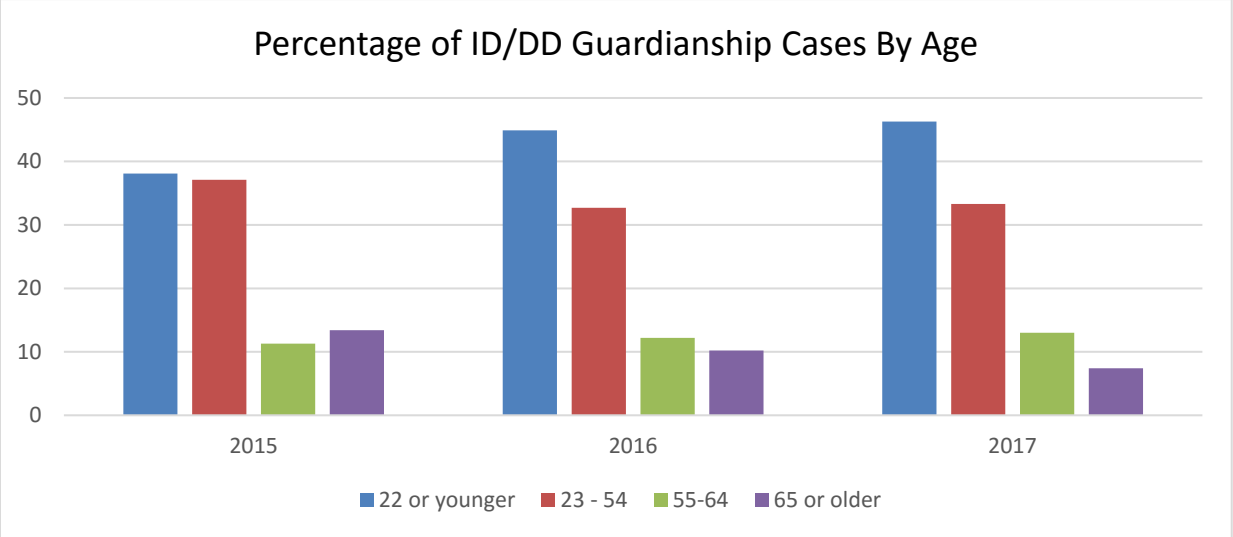
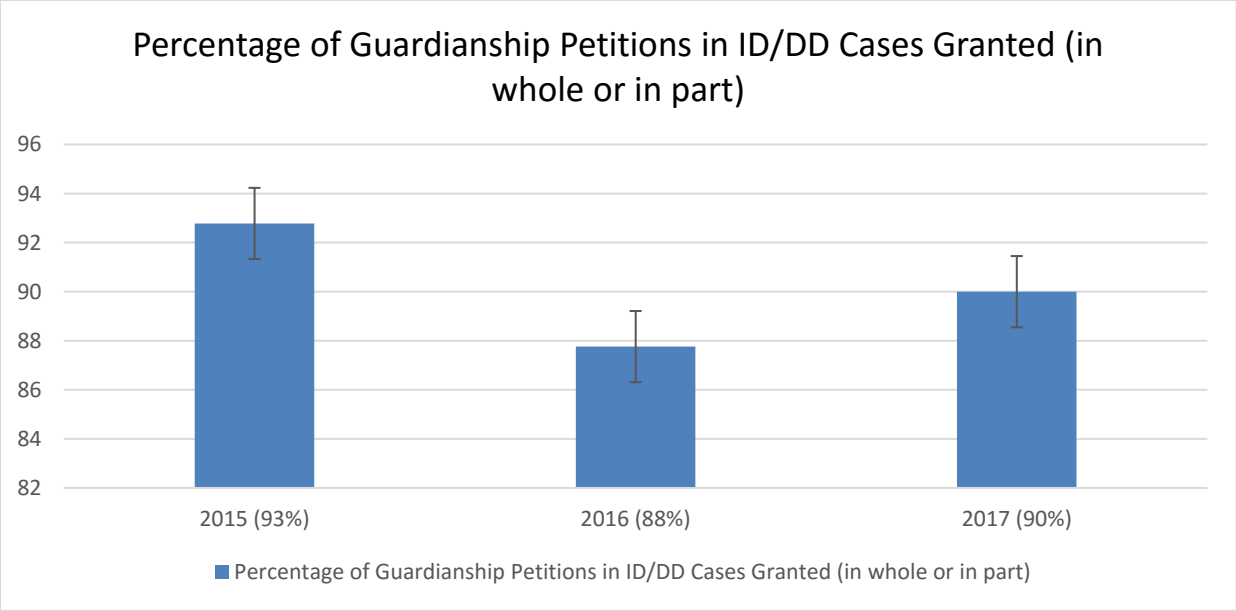




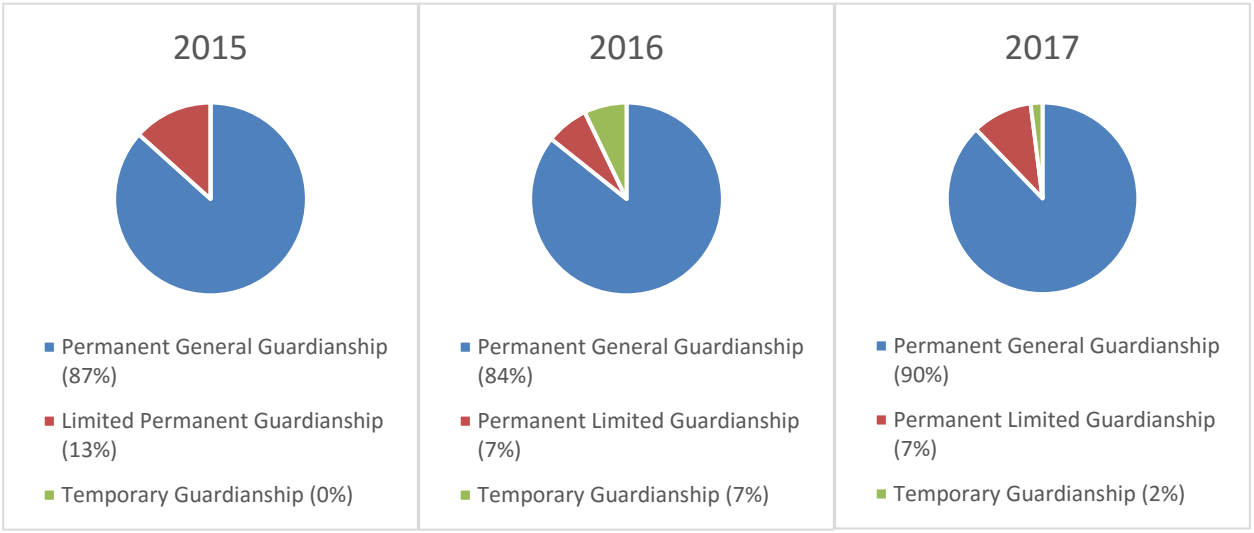
These data-driven concerns regarding ineffective implementation of promising special education agency policy and procedures are consistent with what the project learned from interviews with personnel at DCPS and OSSE. Currently, these agencies reportedly do not comprehensively track the use of alternatives to guardianship, such as SDM, educational powers of attorney, or educational representatives, by adult students in special education. Although several of their trainings incorporate the concept of SDM, there reportedly have been no standalone trainings on that topic presented by these agencies, other than those periodically offered by local disability rights organizations.



Most of the people with ID/DD who faced guardianship petitions were placed under guardianship by the court. The percentage did decrease somewhat from 2015-16, which may be attributed, in part, to the court education efforts to attorneys and legal professionals on the availability of alternatives to guardianship. However, the percentage increased slightly in 2017, which underlines the need for continued training efforts by the court.

When the petitions were granted, most of the individuals with ID/DD were placed under permanent general guardianship, the most restrictive form. This data raises questions about whether courts are using guardianship as the last resort and whether they are consistently appointing the type of guardianship that is least restrictive in duration and scope to meet the person's needs. It may also indicate persistence in stereotypes about people with ID/DD and their ability to be independent with supports, which could lead courts to weigh heavily toward full guardianship instead of alternatives.

Type of Guardianship Granted in ID/DD Cases



The review also indicated that the people with ID/DD in the data set did not seek to have their guardianships reviewed, either through a petition post-appointment for restoration of rights or through the new court guardianship/conservatorship complaint process. There was not a single complaint filed in these cases. There were only three petitions post-appointment requesting restoration of rights, and none of them were filed by the person under guardianship. However, all three were successful and the individual's rights were restored. More education on these due process options for people with ID/DD and their support networks is likely needed, particularly with respect to the complaint process, which has only been in existence for a few years. Careful these consideration should also be given to ensure that tools are sufficiently accessible to and navigable by people with ID/DD.

Pursuant to the DC Guardianship Amendment Act, the first year of court triennial case reviews began in 2018. For this project's data set, 21 such reviews occurred for people with ID/DD through the Guardianship Assistance Program. Only two of the individuals involved were appointed an attorney to help them navigate the process, and none of the reviews resulted in restoration of rights. While a periodic review of the continued necessity of guardianship is a promising DC reform, more time and analysis are needed to determine whether it will have a concrete impact on people with ID/DD under guardianship and whether it will result in any restoration of rights for them.

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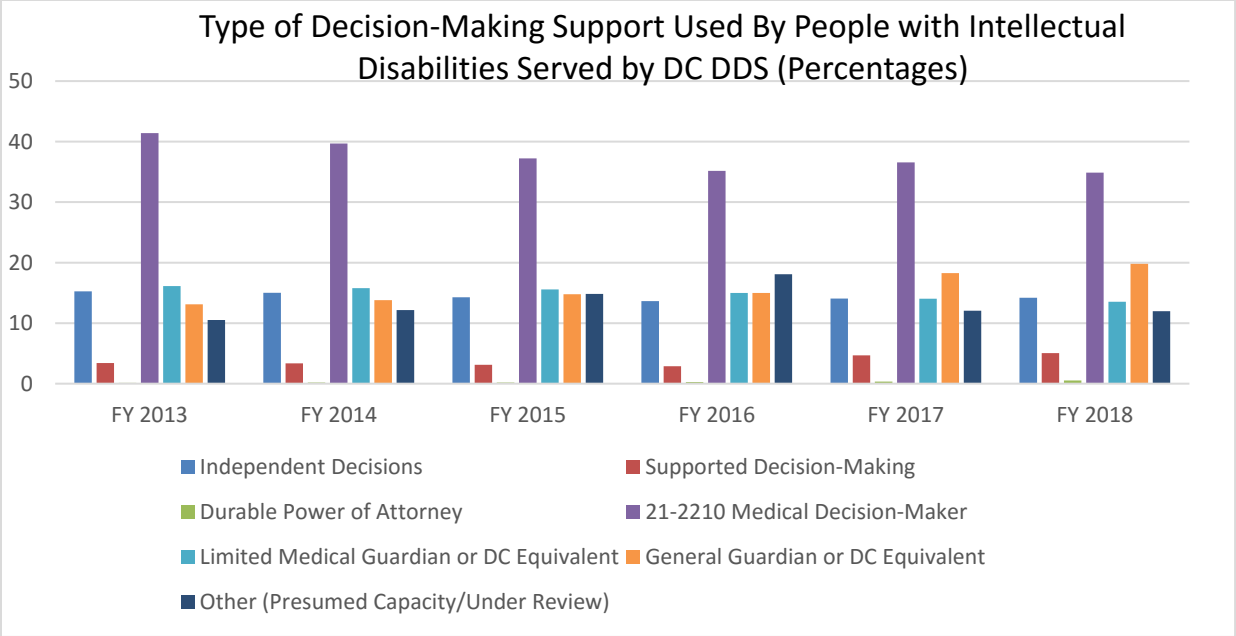

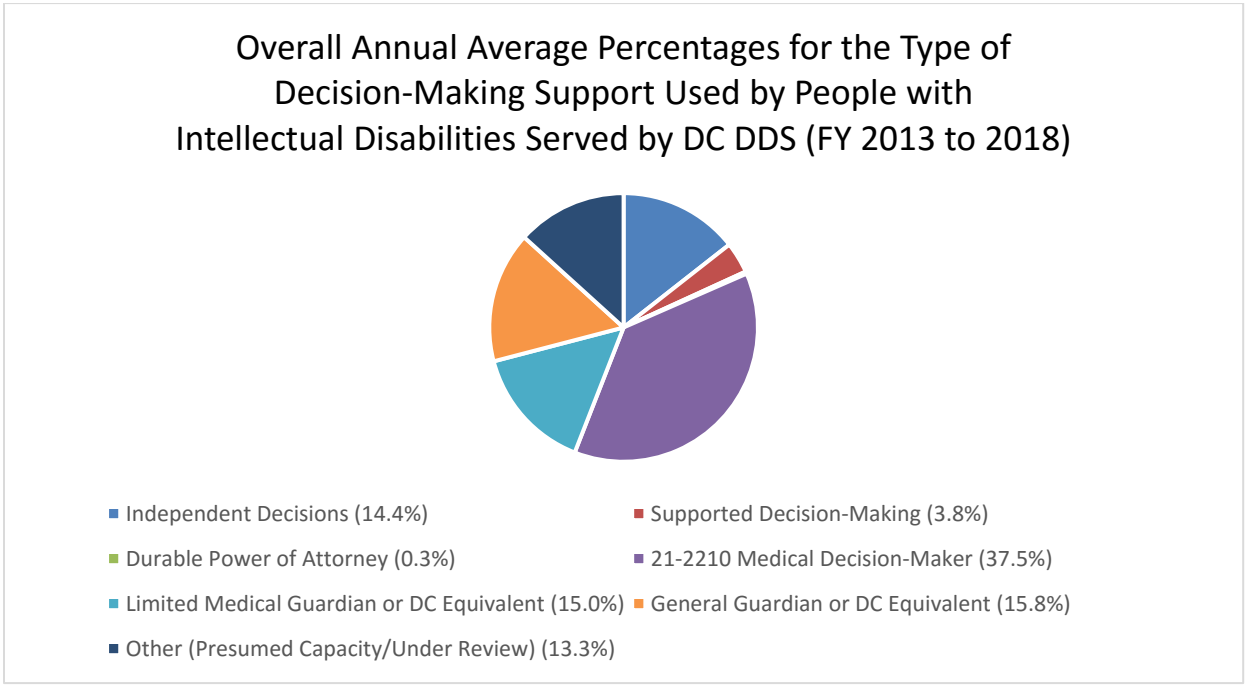

Data from the DC Department on Disability Services on Guardianship and Alternatives

Under DC Law 17-249, the "Health-Care Decisions for Persons with Developmental Disabilities Amendment Act of 2008," the Department on Disability Services (DDS) is required to submit to the Council of the District of Columbia (DC Council) an annual report and plan assessing the current and potential health care decision-making needs for all people served by DDS,[131] which includes DC residents with intellectual disabilities.

This report includes data on the type of decision-making support used, including SDM, Durable Power of Attorney, 21-2210 Medical Decision-Maker, Limited Medical Guardian, and General Guardian. DDS has described the data as a "snapshot," "an approximation, because the numbers fluctuate from day to day as individual needs continue to change." However, the data tells an interesting story about the type of decision-making support that is being legally recognized as used by this population.

While the number of people with intellectual disabilities identified as using SDM has increased over the past five years (from 75 to 111), it has consistently remained the second least-used decision-making support with the DDS intellectual disability system. With the May 2018 statutory recognition of SDM across the lifespan, this statistic may change in the future.

As the data shows, the most common form of decision-making support used by people with intellectual disabilities served by DDS is a 21-2210 Medical Decision-Maker (MDM). In DC, when a person does not have a durable power of attorney for health care and has been certified to lack the mental capacity to make health care decisions by both a qualified medical doctor and a psychiatrist or psychologist, the law turns to a prioritized list of individuals to make those decisions for the person under DC Code 21-2210 of the DC Health Care Decisions Act. For the purpose of DDS' statistics, these 22-2210 MDMs are generally family members or friends who have not been appointed as the legal guardian by the court. The advantage of this law is that it allows the person to receive the health care he or she needs without having to go to court and risk having all his or her other non-medical-related decision-making rights taken away in a guardianship proceeding. The downside is that the law requires non-judicial certifications of the person's incapacity to make health care decisions and does not provide a clear way for the person to challenge the 21-2210 (MDM) designation.[132] In its most recent report, DDS states: "those listed as having a §21-2210 SDM may make many of their own decisions, with or without support, and may simply rely on the designated § 21-2210 SDM in certain situations."

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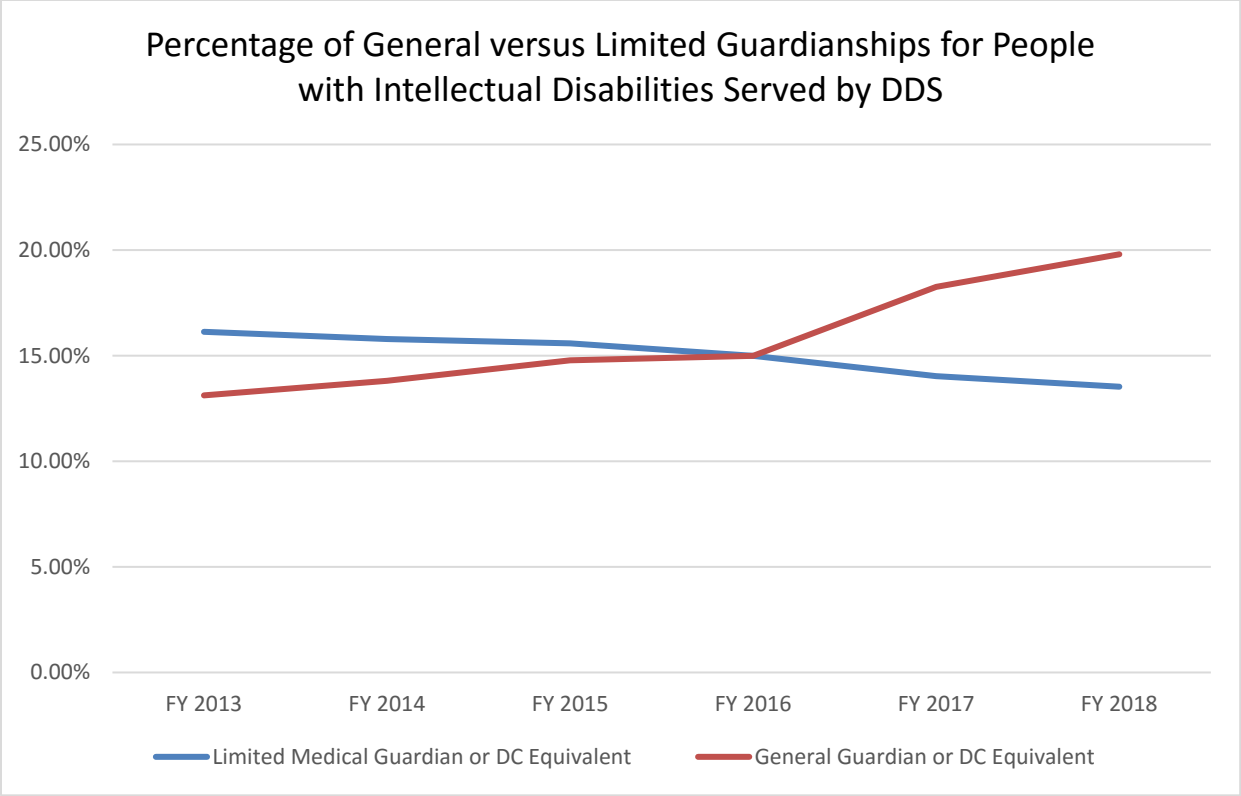
According to this data, the least common form of decision-making support used by people with intellectual disabilities served by DDS is durable powers of attorney, with consistently less than 1 percent of the people served having one that DDS knows about. Durable powers of attorney, unlike 21-2210 MDMs, are a way a person can voluntarily designate someone to act for them in the event they are unable to make decisions themselves, and thus are a less-restrictive option. The high percentage of people who were identified as having 21-2210 MDMs (who, in DDS' system, are usually family members), as compared to the extremely low number with identified powers of attorney, raises concerns that DDS may be over-relying on a more restrictive tool than necessary to support the people it serves. Some of these individuals may be able to voluntarily execute a power of attorney instead, but have not been offered a meaningful opportunity to do so.



Unlike the DC Probate Court data review for people with ID/DD, DDS data indicates that where there is guardianship, it is roughly as likely to be limited as it is to be general. This may be a result of DDS' stated commitment to "the use of lesser restrictive types of decision-making supports whenever possible."[133] It is interesting to note that over time, general guardianship for people served by DDS is becoming more common.

While DC has been a national leader in reforming guardianship and promoting less restrictive alternatives … data demonstrates that there is still a need for further initiatives designed to implement these changes…

Lessons Learned from the DC Experience

As indicated throughout this report, reliable national data on guardianship is scarce, let alone data specific to particular populations, such as individuals with ID/DD. This "deep dive" analysis of guardianship's impact on people with ID/DD within the District of Columbia provides rare data about what the number and types of guardianships are, whether guardianship disproportionately involves young

adults, whether people with ID/DD are using tools to restore their rights, and whether recent legislative and policy reforms have yet had a significant impact. While DC has been a national leader in reforming guardianship and promoting less restrictive alternatives, the previous data demonstrates that there is still a need for further initiatives designed to implement these changes in a way that will significantly advance the decision-making rights of people with ID/DD. For example, data shows evidence of a continued pipeline to guardianship for young adults with ID/DD, despite the special education reforms designed to promote recognition of alternatives for that population.

Lessons for other states

Lessons other states can learn from the DC experience include:

- SDM can and should be recognized as an alternative to guardianship for transition-age youth, including those with ID/DD, in special education. While it is helpful to have a legislative mandate, state law change is not required for implementation of SDM in schools. Existing Family Educational Rights and Privacy Act (FERPA) forms can be modified to document SDM arrangements and ensure parents and caregivers, in their capacity as supporters, receive access to the student's educational information and continue to be invited to IEP team meetings.
- SDM can and should be introduced early in the educational process, ideally beginning in pre-kindergarten. This is particularly true with respect to the development of general decision-making and self-advocacy skills, which are required for effective SDM later in life. Conversations and skill-building efforts relating to decision-making should therefore begin early, well before the student's eighteenth birthday, in order to maximize the chances that less-restrictive alternatives to guardianship will be used.
- Educational agencies and schools must recognize the right of adult students in special education to knowingly and voluntarily execute powers of attorney under state law that designate an agent to exercise their IDEA rights. To do otherwise denies adult students with disabilities an important civil right simply because they receive special education services, which is discrimination based on disability in violation of Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act.
- Given the link between self-determination and community integration, states should include benchmarks related to SDM in their Olmstead plans. These official documents are ways states document their commitment to and plans for providing services to people with disabilities in the inclusive and integrated settings, pursuant to the ADA.
- To minimize the chance that they are overused or misused, any non-judicial alternatives to guardianship that are triggered by some form of certification of a person's incapacity—such as the DC Health Care Decisions Act or the DC Educational Representative process—must: (a) first require the express ruling out of the availability of alternative voluntary options, such as durable powers of attorney for health care or educational powers of attorney; and (b) be easily
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- While state law, regulation, and policy changes to advance alternatives to guardianship are needed, more is required to ensure full implementation for people with ID/DD on the ground. This includes intense and frequent education of people with ID/DD, their families, state agencies, school personnel, judicial and court officers, attorneys, health care professionals, and financial institutions.
- When promising procedures and policies to promote alternatives to guardianship are introduced in schools, educational oversight agencies must develop tracking mechanisms, so that they can trend the way in which IDEA decision-making rights are exercised by and/or for adult students with disabilities—e.g., through SDM, powers of attorney, educational representatives, or Guardianship—so that the impact of these reforms can be concretely assessed and monitored.
- Probate court resource centers that provide prose assistance to people seeking guardianship should also proactively provide information about less-restrictive alternatives that are also available under state law, such as SDM, powers of attorney, representative payees, and substitute or surrogate health care decision-makers.
- State laws should not only ensure that there is an unconditional right to counsel for people in initial and post-appointment guardianship proceedings, but also that counsel is expressly required to zealously advocate for their clients' expressed wishes.
- DC's law promoting limited guardianship is not significantly impacting the scope of an appointed guardian's authority over people with ID/DD, which has tended to be general or plenary in nature, based on recent data. Judicial education to ensure limited guardianships are a viable option for people with ID/DD is needed.
- Although it is too early to meaningfully assess its impact in DC, instituting periodic court reviews of whether a guardianship continues to be the least-restrictive option for a person is a promising DC reform. DC Courts should ensure this review process remains fully funded and should continue to move towards expanding it to more people whose guardian was appointed before 2015. Establishing such review processes should be considered in other states.

The DC Superior Court Probate Branch offers regular orientations to family members on what the legal responsibilities of guardians are. It and other state courts should also train family member and professional guardians on using SDM within a court-appointed guardianship to increase self-determination, as well as train people who have guardians about ways they can access the new complaint process and initiate restoration of rights proceedings.

As one community advocate in DC said, "DC is at the forefront of a lot of important legal reforms designed to promote recognition of the decision-making rights of people with ID/DD. Yet, I still regularly get calls from parents and other family members who say they were told to get guardianship and are not aware of the many less-restrictive options that are available in DC. For these promising reforms to have an impact, a culture shift still needs to happen—at the family level, at the school level, at the judicial level, at the governmental agency level—that recognizes guardianship is not the only game in town for DC residents with ID/DD."

Beyond DC Institutionalization: Donna and Ricardo's Story

A Powerful Love Story

Donna and Ricardo Thornton have a unique love story: They met at Forest Haven, an institution for DC residents with ID/DD. When the institution was shuttered in 1991 by a court order, Donna and Ricardo embarked on a journey together toward self-determination.[134] Their story is one that is marked by significant progress and achievements, made more remarkable by the obstacles they faced. They were told that they could not get married while they were considered wards of the District, but they did just that in 1994.[135] Shortly thereafter, they had a son named Ricky and raised him themselves, despite the common state practice at that time of rssemoving children born to married individuals with ID/DD.[136] They have become powerful activists by serving as leaders of Project ACTION! —a DC-based self-advocacy organization— by giving presentations around the country and testifying before the U.S. Senate.[137] Their story has been featured in the *Washington Post*, on 60 Minutes, and in a 2003 movie starring Kirstie Alley and Delroy Lindo.[138]

Journey to Greater Decision-Making Freedom

Donna and Ricardo have come a long way since Forest Haven, and have other powerful stories to share about how their lives have impacted their decision-making.

Finances

When Donna and Ricardo lived at Forest Haven, they worked at a local fast-food restaurant, but were not allowed to cash their own paychecks. Ricardo described a moment when they decided to take charge of their own money: "The rehab counselor would pick [us] up and drive us in the snow, but then he would leave, and he wouldn't pick us up . . . We had to walk back [in a blizzard]. And that's when Donna said, 'Well, you know what, since we did all this work, why don't we just keep this check?'" Donna recalled they later had to

stand up to the institution's staff. "When we got back to the cabin, they told us, 'You weren't supposed to cash that check.' And I told them, 'This is our check and we spent [it].'" Donna and Ricardo got no "allowance" for that week.

After leaving Forest Haven, Donna and Ricardo were placed in separate group homes, where they had completely different experiences with financial freedom. Donna was taught how to open and manage a bank account. "When I first went into a group home, this lady counselor asked me if I wanted to learn how to open my own bank account . . . And when she taught me how to do this, I was so happy . . . Ever since then I know how to budget and save my money." Ricardo, on the other hand, could only watch as Donna gained more financial independence. "[S]he had her . . . checkbook, so she was able to manage her money . . . I was watching her and thinking, 'Someday I'm gonna do that.'" One day he decided to realize that dream by opening a bank account on his own and depositing his paycheck. However, his group home provider was not happy with his decision. "I got into trouble . . . [because] I didn't ask them to open [it] . . . [I was told] 'Next time you have to come to me so I can assist you so you know what you're doing.'"

Since that time, Donna and Ricardo have lived together for years in their home and both regularly manage their paychecks. Ricardo described his economic empowerment: "Now I put [my money] in my account and check my statement and how much I'm saving and how much I'm spending. [I]t's just being able to have that freedom . . . You can manage your own money and not let people spend your money or tell you how to spend your money. It's a good feeling—like I finally now can make decisions."

Health Care and Domestic Life

Ricardo recalls that Forest Haven made some efforts to connect its residents with counselors and jobs outside the facility. However, he does not believe Forest Haven prioritized education that focused on independence and decision-making outside the institution. He sees the lack of education as significantly impacting not only residents' human rights, but their physical health. For example, there was no formalized sex education. Ricardo recalls: "It was prohibited to talk about it, because if you did it and got caught, you'd get locked up . . . maybe three to four days . . . . If they would have had more education early, [sexually transmitted disease] could have been prevented."

When Donna and Ricardo were living on their own and expecting the birth of their son, they had to deal with assumptions about their inability to make health care decisions. For example, a medical provider did not believe Donna could make a difficult decision about whether to have an amniocentesis. Donna recalls: "[A nurse said], 'They're from institutions, they have no clue of what we're talking about.' … I kept trying to tell her, 'If you just teach us and show us, we can learn this.'" Ricardo said, "I was so proud of [Donna] that she was able to make that decision. Donna went through a period where she was hoping that someone would . . . make that decision for her, but she did it."

Now, Donna and Ricardo more confidently make their own decisions with the support from

people they trust. They are in the process of executing advance planning documents, including advance directives and durable health care powers of attorney. These tools are important to them because, as Ricardo said, "If something were to happen to us, and we're not able to make . . . decisions on our own at that time, hopefully [our agents] will be able to make the decision for us. We put our trust in it, knowing that we're going to be all right." Donna and Ricardo both feel that it is important for people with ID/DD to surround themselves with good supporters who will treat them with respect. "Just remember that we are all on one team, and I would love to have respect. Work with me and know that I'm not perfect, but I'm willing to make a difference."

Chapter 6: Other Stakeholder Experiences with the Guardianship System and Alternatives

Rights Taken, Rights Restored: Tosha's Story from Texas

Tosha Woodward has a developmental disability, and up until she was in her 30s, she was gainfully employed, living as a contributing member of society with no need for guardianship.

Unfortunately, her father was mistakenly told that he needed to file for guardianship for her to live in a group home. This is a common issue for families. Tosha did not want the guardianship, and during the initial hearing, many of her due process rights were violated. For instance, her court-appointed attorney did not arrange for Tosha to participate in the hearing and signed an agreed order that removed all her legal rights including the right to vote, to choose where she lived, and even to work where she wanted.

Guardianship had a serious and detrimental impact on Tosha's life. She ended up in a segregated, sheltered workshop where she was paid subminimum wage for a job that under-utilized her abilities. Her job was to take a bag filled with birdseed from the hand of a peer, rotate her body, and then drop the bag in a bin. Also, immediately after the guardianship was granted, she was moved into a group home with very restrictive rules. "I did not like all the rules that the group home and my guardian made me follow," said Tosha. "I had no freedom and wasn't allowed to make decisions for myself."

Disability Rights Texas learned about Tosha when they met her during their routine monitoring of sheltered workshops that paid subminimum wage. Their attorney informed her of her right to seek restoration from guardianship, and she asked for representation in this effort.

According to Disability Rights Texas, Tosha's guardian and the group home put up many obstacles to keep her attorney from successfully restoring her from being under guardianship, such as putting more restrictions on her life and moving

her outside of the jurisdiction of the court. And then sadly, her guardian died, which made for a more complex and lengthier process to finally achieve restoration for Tosha.

When Disability Rights Texas was finally successful at getting Tosha's rights restored, she cried in relief, "I am so happy to have my freedom back. I get to make my own decisions again about where I work and live." She is now working again in the community making a fair wage at a job she enjoys.

Tosha's story illustrates the concerns NCD raised in its 2018 report with respect to the implementation of guardianship regimes, including barriers to due process in initial guardianship proceedings, lack of zealous representation by some court-appointed attorneys, the expansive loss of rights, and barriers to pursuing restoration. But it goes further than that by highlighting the restrictive impact guardianship can have on people with ID/DD, depending on the actions of the more restrictive living and working environment, with guardian. In Tosha's case, she was moved to a hardly a clear way out. It also illustrates how difficult it is for people with ID/DD to get information about their rights, whether from the guardian, the courts, the group home system, and in Tosha's case, a sheltered workplace that didn't provide any information to her. If the Texas protection and advocacy system hadn't run across Tosha during a routine monitoring, would she have been able to get her rights restored?

In Their Own Words: Other Lessons Learned from Stakeholders

NCD gathered stories about experiences with guardianship and alternatives and their perceived impact on people with ID/DD through a variety of methods, including online story collection, a focus group, and one-on-one interviews. This resulted in input from people with ID/DD, family members, and other stakeholders, including special education advocates, state employees, guardians, or administrators of guardianship programs, and staff who provide transition services to youth with ID/DD. Qualitative information was collected from more than 80 respondents from 19 states and the District of Columbia. NCD identified several themes within these stakeholder stories that shed light on the perceived impact—both positive and negative—that guardianship and alternatives have on people with ID/DD. These themes are consistent with many of the findings and recommendations in this report, which seeks to balance the importance of promoting the self-determination for people with ID/DD with the recognition of the existing state legal systems designed to provide safeguards for this population.

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Reasons Adults with ID/DD Become Subject to Guardianship

When asked when an adult with ID/DD gets put under guardianship or conservatorship, most respondents identified 18 as being the magic age at which such legal intervention is or should be sought.

- One guardian stated: "[G]uardianship should be in place by their eighteenth birthday. Otherwise, it is impossible to be included in their medical care or finances."
- A family member agreed: "At or by the age of 18, since that is when medical providers no longer include the parents in conversations about medical care. It is also when SSI begins and management of this as well as waiver supports starts."
- A family member responded: "When [people with ID/DD] turn 18, unfortunately, parents are led to believe it is needed in order to maintain involvement in their child's life or to get access to services."
- Another family member indicated guardianship referrals for people with ID/DD happen "[o]ften at or around 18, upon the advice of doctors, teachers, and others."

As indicated in Chapter 2, the educational system was frequently seen as the reason behind such referrals, but there were other reasons cited as well. Many respondents included the medical profession as a common source of guardianship referrals. For example:

- A disability rights attorney reported: "Medical providers also push for guardianship when the person presents for care and the provider believes they are not competent to consent to medical treatment."
- A respondent with ID/DD stated: "Doctors who don't know you will make a decision that you are incompetent."
- A family member reported that some providers may exclude supporters unless they have guardianship: "There has been involvement with a misinformed medical provider and says [guardianship] is required in order for individuals who support the person to be involved or support the individual with the issue."
- A family member described her experience: "Doctors thought there were a fifty percent chance he would come out of the coma and a five percent chance he would be able to live independently. [Based on that,] I thought we needed the conservatorship in order to conduct business on his behalf, but as I stated before, it was not needed. We even refinanced our mortgage without it—I explained it to the bankers/realtor, but they said he could sign for it."

Another referral source, according to respondents, comes from attorneys and judges.

- One family member said: "Schools and attorneys tell parents that they need to get Guardianship to protect their handicapped son [or] daughter when they turn 18 (or 21). I feel this is misleading! guardianship strips a person of their rights . . . [E]ssentially they become a piece of property."
- Another parent recalled her experience with an attorney: "My divorce attorney told me about power of attorney as an option, but when he met my son, he was unsure if my son understood what giving

someone POA meant . . . I [now] have medical power of attorney for my son."

- An additional family member reported that an attorney recommended guardianship for her nephew with ID/DD because it would make it "easier" for them to set up a trust for him.
- An attorney described an interaction she once had with a judge: "I think of a conversation with a judge 15 years ago about a person with Down syndrome. The judge told me that of course anyone with Down [syndrome] should have a guardian by virtue of the diagnosis. We have come a ways, but there is so much farther to go."

Based on several respondents, one of the reasons people obtain guardianship is because of what they fear may happen without it—fear of being taken advantage of, fear of dangerous choices, and fear that supporters will be cut out of the decision-making process. For example:

- One parent said: "Parents fear their child will be taken advantage of and that their own advocacy will not be heard. Parents do not think their children will grow and develop beyond what they have accomplished by the time they are 18 and fear they will never be able to make important decisions and need to be protected."
- Another parent described the difficult choice she faced: "Guardianship was difficult to get for our son. Some people said, 'He looks normal. Why do you want it?' . . . Left on his own, someone could take advantage of him and take his money. Before we had guardianship, our son thought he was spending one-hundred dollars to take a class, but he was actually charged one-thousand. It took my husband and me two months to get the money back."
- According to another respondent, a parent seeks guardianship when he or she "fears that they will be shut out of helping to make decisions for a family member who does not communicate in traditional ways or quickly enough during medical or financial discussions."
- One family member who is a standby partial guardian of a sibling with ID/DD said people turn to guardianship because of "Fear. And it's not an irrational fear. Our adult service system has a long way to go to [prove] that it can properly care for people with IDD. Our communities have a long way to go to fully accept and care for all community members in an inclusive way."

[O]ne of the reasons people obtain guardianship is because of what they fear may happen without it …

Perspectives on the Impact of Guardianship on People with ID/DD

When answering whether they thought guardianship or conservatorship influences or changes the way people with ID/DD are treated, most respondents answered in the affirmative, although many of the responses focused on whether the guardian was skilled and knowledgeable (or not), highlighting how individual

experiences within a system may vary considerably. Some respondents pointed to perceived positive changes for people with guardians. For example:

- A family member stated: "Others know the adult with ID/DD has an advocate and, in our case, a very active and involved advocate. They know they cannot take advantage of him and, more importantly, know it is OK to be helpful without fearing they may be asked for considerably more help."
- A case manager reported: "Ones without guardians are way too easy to exploit, abuse and/or neglect."
- A family member guardian said: "Those individuals [in guardianship] may be viewed as safer because there is a team of people keeping watch over their best interests."
- Some participants, mostly family member guardians, described what they felt to be the beneficial aspects of guardianship. For example:
- A parent of a person under guardianship stated: "We feel we can be proactive rather than reacting [to] a problem. Having guardianship makes it easier to speak and make [decisions] with professional[s] — medical and governmental—about our son."
- Another parent and guardian agreed: "My son has medical as well as cognitive issues. It was imperative that his health and well-being would be overseen by us, his parents who have his best interests at heart. Having guardianship has meant that we can make medical decisions and program decisions that benefit him, as no one else knows him as well as we do. He is incapable of understanding these things and he needs protection, which we can supply as his guardian."

Others saw benefits when guardianship is used with SDM to encourage the development of decision-making skills and self-determination.

- One disability rights attorney recalled her experience with a client who was placed in guardianship: "My client, who has an intellectual disability, was found wandering the streets at the age of 19 after her father died. Having completed high school, she was no longer receiving services and was unable to care for herself. She was placed in a nursing home and put under guardianship. Her guardian was an incredible advocate for her. He got her connected with services, which truly allowed her to grow. Eventually, she completed a training program and began full-time employment with benefits. Her guardian recognized the growth in skills and independence that had happened and worked with me to assist my client in terminating her guardianship in favor of supported decision-making. Now my client makes all decisions."
- Another parent and guardian described how they incorporate SDM in the guardianship: "[W]e strongly support our daughter in self-direction, on her own, as much as possible . . .

She is a recipient of our state's DD waiver program . . . It supports therapies, direct support services such as transportation, and community or homemaker direct support. This helps her with supported decision-making to have an improved quality of life in the community."

Many stakeholders who responded to this question saw a negative change in the way society treats people with ID/DD after a guardian is appointed. For example:

- A family member stated: "In my experience, the person [under guardianship] is then seen as having nothing to contribute to decisions about any aspect of their life. Instead of presuming competence people begin to presume inability and lack of intelligence."
- Another family member agreed: "They are viewed as people who need to be protected, who do not have preferences, stresses, interests, desires . . . and will likely never achieve independence or full active lives in the community."
- A person with ID/DD who does not have a guardian stated: "I've seen people not be treated like humans—like they're just a disability."
- A family member guardian stated: "They talk to me, not him—it's like he is not there beside me."
- A social worker said: "They may be looked down upon as being unable to care for themselves or meet their own needs."
- A family member from Kentucky pointed to "lower expectations, less opportunities, seen as less valuable."

Some respondents noted that guardianship is sometimes used as a tool for control. As one attorney explained: "In [my state], providers are not prohibited from becoming guardian over those who use their services. Sometimes this has been done 'benevolently,' other times it has been done manipulatively to prevent the person from leaving services or changing service providers."

Some respondents mentioned due process concerns, specifically how easy it is to obtain guardianship over a person with ID/DD and how difficult it can be to terminate:

- One family member of a person with ID/DD stated: "I am aware of a handful of individuals who would like to have their rights restored and their efforts are stalled by a lack of legal support to execute the proper documents. The[y] are unaware of the process. Those served by service providers without family have no resources to terminate guardianship, despite having an interested party attempting to make it happen."
- One professional described not knowing what to do when a person she supported wanted to fire his guardian: "I felt that I don't really know what to do, because there was always talk about getting guardianship. There was never talk about . . . reinstating rights. [Guardianship is seen as] the one-way ticket… There wasn't an

idea: How do we reverse this?"

Other respondents described people with ID/DD experiencing a regression of their decision-making abilities while under guardianship:

- One family member stated: "[My family member under guardianship] has overcome many obstacles and her potential is unknown, but one thing she is not, is incompetent. Nobody cares. She is regressing. She is learning to be helpless and does not want to live this way. Watching what is happening to her reminds me of experiments I have read about like the Stanford Prison experiment, and how over time you become the person you are made to be."
- A sibling of a person under guardianship stated: "My brother has a severe intellectual disability and autism. He's primarily nonverbal and is dependent on others for many of his daily life activities . . . I think the lowered expectations associated with my brother being under guardianship have caused him to lose the progress on skills and independence that he was making towards the end of high school. In many ways, he has regressed and become more dependent on others. It's very frustrating both as his sister and as a researcher to see this happen and be limited in intervening."
- Some respondents pointed to both positive and negative consequences. For example:
- One family member stated: "I hate to say this, but in general, I feel that it makes people treat disabled people like they are children incapable of doing anything by themselves. In extreme cases like my cousin, [however, guardianship] is absolutely vital."
- Another family member in a different state agreed: "It can be associated with lowered expectations for individuals with ID/DD, but also the perception of more oversight and regulations as it is not the person with ID/DD making most decisions."
- An administrator of guardianship explained: "We have witnessed both positive and negative changes: As decision-makers for individuals supported in guardianship, agencies are hard pressed to go against the wishes of the guardian, especially if we disagree with plans for the individual. I am concerned that sometimes, treating physicians and other professionals may not embrace the person, instead there may be a focus on the guardian/decision-maker."

Perceptions on the Impact of Alternatives to Guardianship on People with ID/DD

Many respondents described how they use alternatives to guardianship, such as powers of attorney or SDM, and the benefits of using these options.

- One mother described her son's experience: "supported decision making has given my son a very good experience of forming the life that he wants while we ensure his safety and locate a great network of support. People with intellectual disabilities should be able to

create a life that they enjoy filled with their desires."

- A respondent explained how her family member has become more confident since guardianship was terminated: "I continue to be the representative payee, and I am considering terminating that role in light of what I now know about supported decision-making. I know that my family member will continue to need help handling interactions with Social Security, Medicare, et cetera, but I would like to return the right to decide how his SSD is spent [on] him. He is already more confident and assertive since the conservatorship termination, and I expect him to continue to grow as he takes ownership of his decisions with my support."
- When it comes to people with ID/DD, some recommended considering and using a combination of alternatives. For example, a respondent reported: "My sibling has a power of attorney to assist her with her medical, financial, and legal needs. In addition, [she] has a representative payee to assist [her] with managing her Social Security benefits. In addition, my sibling has a formal circle of support to assist her with helping to address the things that are important to her: her business, her employment, finding/hiring direct support workers, managing her supports, and living a good quality of life."

Others cautioned against overzealously promoting alternatives to the point where guardianship became a "dirty word." For example:

- A lawyer and family member agreed with the exploration of alternatives, while recognizing that guardianship may remain a valid option in certain cases: "As long as the concept of using the least restrictive alternative/intervention appropriate for that person is used, I have seen these alternatives to guardianship be successful. However, guardianship should not be turned into a dirty word. My brother needs a guardian for his own safety and welfare, but, of course, that does not remove the obligations in [Massachusetts] of the guardian to take into account his express desires and to only exert the amount of authority necessary."
- One parent expressed concern that people were too often being discouraged from getting guardianship and described an "anti-guardianship movement" that could be perceived as an "attack on families" of people with ID/DD.

Importance of Self-Determination for People with ID/DD

Another common theme expressed by some self-advocates, family members, and professionals is that promoting self-determination can have a host of positive benefits for people with ID/DD.

- As one self-advocate explained, "My belief is that a person with a disability can get confidence with making decisions from their family members, when they figure out what they need. My belief is that they get support from their family members and, later on . . . they pretty much got a skill to make decisions and that is like adaptability."

- A parent of a person with ID/DD also described the confidence that can come with decision-making: "In my opinion, the key is teaching [my daughter with cerebral palsy] decision-making skills and helping her feel confident enough to express her opinions and decisions. However, I knew very early that my daughter was very capable of making her own decisions, regardless of what others thought."
- An attorney recounted the experience of her client whose guardianship was terminated: "My client had her guardianship terminated in favor of using supported decision-making. This arrangement has allowed her to exercise self-determination and independence. One of the first things she did was sign up for her benefits at work. It means so much to my client to be able to make her own decisions and have control over her life."
- A parent expressed how important it was to involve people with ID/DD in decisions about health care. "More than 20 years ago when my daughter was a teen, her doctor recommended that she have surgery to restructure her hip socket, which would help prevent arthritis and other painful conditions. I sought a second opinion, which validated the recommendation. My daughter had the surgery, which was very painful, required a body cast and a fairly long recovery period. I made this decision for her, but she suffered. I decided then that I would never do that again, without her understanding and agreement, except in dire circumstances. Since that time, we have always discussed her health care and made decisions together."

Societal Biases Impacting the Decision-Making of People with ID/DD

Several respondents also described the negative assumptions people with ID/DD have faced regarding their ability to make their own decisions or the need by others to control their decisions.

- A person with ID/DD described the reactions he received after he purchased a house: "When I got the house . . . a lot of the people were shocked . . . [T]hey didn't think I deserve to have anything that they have because of my disability . . . But for the first two years I didn't think [the house was] mine . . . I thought somebody is going to come to me and tell me 'Get your retarded butt out of my house, it's not yours.' . And I was paying the mortgage and everything but because for so many years I was told what I couldn't have, what I couldn't do, I didn't believe the house was mine. And then when I realized the house was mine, I cried."
- A parent explained: "Often people with visible [ID/DD] are assumed to be less than whole and not capable of knowing what they want or what they're doing. For instance, a waiter will often address the companion of the person with [ID/DD] when taking an order in a restaurant, rather than asking the person directly."
- A self-advocate agreed: "[W]hen you have a disability, everybody sees themselves a

bit above you and they see themselves a bit above me, because, even [in] my personal life, I have very close people who wanted to control me . [T]hen they disrespect you, but they think they [are] doing something for you. [B]ut sometimes, people they want to control you."

The Power of Communication in All Forms for People with ID/DD

Communication is a vital part of decision-making, and some of the assumptions made about people with ID/DD may spring from their non-traditional method of communication.

- As stated by a parent of an adult child with ID/DD, "[P]eople with [ID/DD] who don't use words to communicate or whose language is hard for others to understand, are assumed to be less than capable of having their own opinions. Not true . . . [W]e need to understand how the individual with [ID/DD] communicates, and share that information, so that the voice of the person with [ID/DD] will be heard."
- Another family member agreed: "Most people who have trouble with traditional communication because of the pace or complexity of the interaction are perceived as someone who needs help to make decisions."
- A self-advocate told a story about how a person who did not communicate through words was treated: "[S]omebody that I knew long time ago… he was throwing a fit and was making noises and [the provider] thought that he was acting up . . . [T]hey got mad at him and got ready to write him up. [R]ather than enforcement, he is very intelligent. He should've been able to [be supported to] communicate like [with] a notepad or a keyboard."

When supporters and others learn how to effectively communicate, it can unlock the person's decision-making ability. A self-advocate in DC recalled her experience of learning how to creatively communicate with a peer who did not communicate verbally: "When I was in school riding the school bus, I ran into this pretty young girl . . . I asked the bus driver who [she was] . . . He said she can't walk or talk, and I said . . . 'Not now, but she will.' and by the end of that school year . . . me and her came up with a way of talking. She talks [with] her eyes [by blinking] . . . It's just a different form or way of talking."

The Impact of a Lack of Opportunity to Make Decisions on People with ID/DD

Multiple respondents discussed how a lack of education on decision-making negatively impacts people with ID/DD. For example:

- One parent of an adult child described her feeling that people with ID/DD are not always encouraged or asked to weigh in on their own decisions or encouraged to advocate for themselves: "[M]any people] with [ID/DD] are not taught to make their own decisions or given the go-ahead to do so. We need to teach all children, including those with [ID/DD], about decision-making and the give and take that's sometimes involved. They need to learn to choose in

small ways whenever possible."

- A self-advocate who regularly gives following story: "One year we was asking people what they wanted out of life and this one man, I think he was in his fifties, he started crying, and we was asking him why, and he said that that was the first time anybody ever asked him what he wanted, and he grew up in the system and nobody cared about what he wanted."
- Another self-advocate with ID/DD, on the other hand, recalled the advice she received that not everyone does: "My mother always told me to speak up so that I won't be left behind."

"One year we was asking people what they wanted out of life and this one man, I think he was in his fifties, he started crying, and we was asking him why, and he said that that was the first time anybody ever asked him what he wanted, and he grew up in the system and nobody cared about what he wanted."

Many respondents tied the lack of education on and opportunity for decision-making to the effects of living in a more restrictive community setting such as a group home. Several self-advocates described how such a living situation shaped their perspectives on decision-making and self-determination. One person with ID/DD wondered how people would learn from their mistakes if they are not allowed to make any: "I feel like a group home is another small institution. [I]f somebody keeps telling you [not to] do something, how are you going to learn from something?"

Chapter 7: Findings and Recommendations

As a supplement to the corresponding section in the 2018 NCD report, below are additional findings and federal level recommendations designed to improve the experience of people with ID/DD in systems of guardianship and in the implementation of less-restrictive alternatives.

Key Findings and and Recommendations

Finding 1: The lack of data on existing guardianships and newly filed guardianship includes information on the specific nature of the person's disability, thus making it difficult to have reliable state and national information on how guardianship systems impact people with ID/DD and whether that population is likely to be in limited or full guardianship than people with other disabilities.

Recommendations:

- The Social Security Administration has data based on disability-related eligibility Listings. Therefore, it should not only conduct data on whether individuals it serves are subject to guardianship, but trend it against the type of disability.
- Offer states incentives and technical assistance with developing electronic filing and reporting systems that collect basic information about guardianships, including the alleged disability of the person served—as well as their age—among the other information recommended in the 2018 NCD report.
- The National Core Indicators (NCI) website should also specify, on a state-by-state basis, precisely to what population of people with ID/DD the state is administering its survey, so that one can assess whether the data collected is truly representative of the full population of people with ID/DD in that state.

Finding 2: People with ID/DD currently are at higher risk for guardianship because of the school-to-guardianship pipeline.

Recommendations:

- The U.S. Department of Education OSERS renewed its previously archived 2017 "Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities," which recognized the serious implications of guardianship and encouraged

Key Findings and and Recommendations, *continued*

schools to recognize SDM and other less restrictive decision-making support for adults in special education. OSERS should do more to promote implementation of this guide at the state and local level, including requiring State Educational Agencies to:

  - Ensure robust and repeated trainings of educational professionals at the agency and school level on options for supporting the decision-making of adult students with disabilities, including people with ID/DD, that are less-restrictive than guardianship.
  - Create a modified FERPA form for the transition process that documents SDM arrangements that ensure parents and caregivers can support transition-age youth in making educational decisions after rights transfer to them.
  - Ensure local school systems do not unlawfully discriminate against adult students with disabilities who wish to exercise their civil right to execute a power of attorney under state law.
  - Develop tracking mechanisms to determine how decision-making rights are exercised by and/or for adult students in special education to assess and monitor the use of guardianship and alternatives by transition-age youth.

- OSEP should instruct its Parent Training and Information Centers to prioritize and provide meaningful training on school-to-adult transition and alternatives to guardianship.
- The Department of Education should issue a "Dear Colleague" letter to all teacher education programs and vocational rehabilitation agencies urging them to cover the full range of decision-making options in their transition programming and instruction of accommodations for people with ID/DD.
- The Department of Education should issue regulations and/or guidance clarifying the requirements for states that, pursuant to their own state law, create an educational representative appointment option for adult students who cannot provide informed consent for their special education services, pursuant to IDEA (30 U.S.C. § 1415(m)(2)) and its regulations (34 C.F.R. § 300.520(b)). When such appointment is triggered by a parent's request or an alleged certification of incapacity, states must require that: (1) less-restrictive options, such as educational powers of attorney or other voluntary delegation by the student are exhausted first; and (b) such appointments are easily challengeable by the students involved through, for example, a mere objection rather than by a due process hearing before an administrative law judge.

Key Findings and and Recommendations*, continued*

Finding 3: A minority of states have guardianship provisions that are applicable solely to people with ID/DD, as opposed to other alleged disabilities. While some of these statutes incorporate additional procedural safeguards, there is not demonstrable proof that they are advancing the due process and substantive rights of people with ID/DD in practice and, in treating people with ID/DD uniquely, may be promoting unfavorable stereotypes about the inherent capacity or incapacity of this population. In addition, these statutes could represent an ADA violation for discriminating against people with different disabilities.

Recommendations:

- The U.S. Department of Justice should take the position that the degree of due process in a guardianship matter under state law or practice should not be different for people with ID/DD simply because of their diagnosis, and states that have such statutes or practices are engaging in discrimination under the ADA.
- The state adult guardianship court improvement program that NCD recommends be created and funded in the 2018 NCD report should require that guardianship be used as a matter of last resort and that the person's functional abilities be assessed on an individualized basis rather than on the basis of the person having an ID/DD, consistent with the Uniform Guardianship, Conservatorship & Other Protective Arrangements Act.

Finding 4: While more states should advance alternatives to guardianship in their state laws, regulations, and policies, more is required to ensure that these changes are fully implemented on the ground, creating a cultural shift at the judicial, governmental agency, and business levels that significantly recognizes and advances the decision-making rights of people with ID/DD.

Recommendations:

- DOJ should issue guidance to states on their legal obligations pursuant to the ADA in the context of ensuring that guardianship should be a last resort that is imposed only after less-restrictive alternatives have been determined to be inappropriate or ineffective. This guidance should include requirements that states consider including benchmarks related to SDM in their Olmstead Plans.
- The state adult guardianship court improvement program referenced above should require states to:
    - Not fund probate court resource centers that only provide pro se assistance to people seeking guardianship. Those resource centers should also provide people with information about less-restrictive alternatives under state law, such as SDM, powers of

Key Findings and and Recommendations, *continued*

attorney, representative payees, and substitute or surrogate health care decision-makers.

- Ensure that there is an unconditional right to counsel for people in initial and post-appointment guardianship proceedings and that counsel is expressly required to zealously advocate for their clients' expressed wishes.
- Provide judicial and attorney trainings on the availability of less-restrictive options for decision-making support under state law.

- The DOJ should issue guidance to states on how to minimize the risk of overuse or misuse of involuntary, non-judicial alternatives to guardianship, such as those in educational or health matters, which raise due process concerns. States should legally require ruling out voluntary options—such as SDM and powers of attorney—before such involuntary options can be used. Those involuntary options should also be easily challenged by the person.
- The U.S. Department of Health and Human Services should explore ways to facilitate decision-making support for people with ID/DD, particularly for those who may not have a large network of trusted family members and friends. This should include providing funding to support:
  - Community services such as health advocate programs, in which a supporter attends medical appointments, assists the supported person with understanding and making major medical decisions, and acts as a facilitator between the supported person and his or her doctor.
  - Financial case management services, including regular meetings with supported individuals to discuss budgeting, establishing direct debit and deposits, and assisting in the management and recertification of public benefits.
  - Educational advocate services to help adult students with ID/DD understand and make educational decisions. Examples of this type of support could include attending IEP meetings, assisting with transition planning, and facilitating communication between the supported person and education officials.

Finding 5: Despite the existence of restoration of rights procedures in many state laws, many people with ID/DD and their families are unaware of those options, let alone the broad array of less-restrictive options. People with ID/DD may therefore remain in guardianships that are overbroad or undue for most of their lives.

Key Findings and and Recommendations*, continued*

Recommendations:

- The state adult guardianship court improvement program referenced above should require states to:
    - Regularly notify people in guardianships, their guardians, and other interested parties in their life that guardianship need not be permanent and that there are concrete ways to pursue restoration of rights.
    - Periodically review guardianships to determine whether they remain the least restrictive option or should be modified or terminated.
    - Train family and professional guardians on using SDM within a court-appointed guardianship to increase self-determination and the potential for restoration of rights.
    - Train people in guardianship on ways in which they can complain about their guardian and initiate restoration of rights proceedings.

Finding 6: There is a dearth of reliable data on the number of adult abuse, neglect, or exploitation cases in which the perpetrator is the court-appointed guardian or other substitute decision-maker of the victim. According to the National Adult Maltreatment Reporting System (NAMRS), eighteen states do not collect any perpetrator information.[139] Of the states that do track general perpetrator information, the vast majority do not collect specific information regarding a perpetrator's role as the court-appointed guardian or other substitute decision-maker.[140] Although the NAMRS requests data from states about the perpetrators' role as the victims' court-appointed guardian or other substitute decision-maker, in 2017 only four states submitted data for the start of the investigation. No state has ever submitted data to NAMRS for the end of the investigation.[141]

Recommendations:

- States should continue to be encouraged through the NAMRS and other mechanisms to collect, track, and report the number of cases in which perpetrators are the victims' court-appointed guardian or other substitute decision-maker.
- The state adult guardianship court improvement program referenced above should require that state courts review the annual reports of guardians for signs of unusual or deficient accounting and signs of abuse and neglect.

Appendix A: Analysis of ID/DD Specific Guardianship/Conservatorship Statutory Provisions

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
Alabama Ala. Code § 12-13-21 et seq.	▪ Defines "developmentally disabled" person as a person "whose impairment of general intellectual functioning or adaptive behavior meets the following criteria: (1) It has continued since its origination or can be expected to continue indefinitely; (2) it constitutes a substantial burden to the impaired person's ability to "perform normally in society"; (3) it is attributed to one or more of the following: "including intellectual disability, cerebral palsy, epilepsy, autism, a condition found to be 'closely related' to intellectual disability because it 'produces a similar impairment'" or requires similar treatment or services, or dyslexia related to these conditions. ▪ "Perform normally in society" is not defined by the statute, and the language used in the statute to refer to specific disabilities is outdated. ▪ Guardianship for a developmentally disabled person shall be used "only as is necessary to promote and protect the well-being of the person, including protection from neglect, exploitation, and abuse; shall be designed to encourage the development of maximum self-reliance and independence in the person; and shall be ordered only to the extent necessitated by the person's actual mental and adaptive limitations." ▪ The court may appoint as guardian for a developmentally disabled person "any suitable person or agency, public or private, including a private association or nonprofit corporation capable of conducting an active guardianship program for a developmentally disabled person." The court cannot appoint the Department of Mental Health as guardian or any other agency that directly provides services to the person with ID/DD. ▪ A petition for the appointment of a guardian may be filed by "an interested person or entity," or "by the individual." "Interested person or entity" means an adult relative or friend, an official or private agency, corporation,

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	or association "concerned with the person's welfare," or any other person the court found suitable. ▪ While it does not specifically cross-reference the standard Alabama guardianship statute, this provision does not set forth separate and specific procedures for the appointment of a guardian. The impact of the two provisions above on guardianship for persons with ID/DD is not evident from the text.
Arizona Ariz. Rev. Stat. § 36-564 et seq.	▪ Appointed under and governed by the same procedures, with clarification that guardianship and conservatorship "shall be utilized only as necessary to promote the well-being of the individual . . . and shall be ordered only to the extent necessitated by the individual's actual mental, physical and adaptive limitations." ▪ Department of Economic Security may request the appointment of a guardian if it feels a guardian would be in the person's best interest. When no one is available to act as the guardian, the Department must notify the public fiduciary in the county where the person receives services of "the need for a guardian."
California Cal. Health & Safety Code Div.1, Pt. 1, Ch. 2, Art. 7.5, §§416 to 416.23	▪ Governed by the same procedures, with main exceptions listed below. ▪ Provides that the court may appoint the Director Developmental Disabilities as guardian or conservator of the person and estate, stating that the typical order of preferences for that appointment do not apply. ▪ Sets forth unique requirements for the Director, such (a) payment of a single official bond, rather than bonds per individual; (b) responsibilities to maintain close contact with the person, no matter where they live in the state; "act as a wise parent would act in caring for his developmentally disabled child"; and "permit and encourage maximum self-reliance" on the part of the person; (c) provide at least an annual review in writing of the physical, mental, and social condition of the person. The Director may receive reasonable fees for such services. ▪ Provides additional requirement that regional centers provide the court with a "complete evaluation" of the person, including "current diagnosis of his physical condition prepared under the direction of a licensed medical practitioner and a report of his current mental condition and social

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	adjustment prepared by a licensed and qualified social worker or psychologist." ▪ Requires the court to appoint an attorney to represent the person if he or she does not have attorney, with the person paying the cost if able. In non-ID/DD cases, appointment of an attorney for the person is at the court's discretion, unless the person requests one. ▪ Allows for exceptions to person's attendance at the hearing that is similar to those in non-ID/DD cases. ▪ Requires that when a person will not be present at the hearing, that the psychologist or social worker who evaluated the person visit and "be prepared to testify as to his or her present condition." However, the psychologist or social worker in question is required to consult the person to determine the person's opinion concerning the appointment" and must be prepared to testify as to the "person's opinion, if any." In non-ID/DD cases, a court investigator is required to interview the person, petitioner(s), and proposed conservator(s), spouses/domestic partners, and certain relatives; make investigative findings; and submit a report to the court. ▪ No costs or fees may be charged or received by the county clerk for any official services performed, including the filing of the conservatorship or guardianship petition.
Connecticut Conn. Gen. State Ann. 45a 802h §§-669 to -693	▪ Intellectual disability diagnosis is part of standard for appointment of a guardian, but the person must also be found to be unable to meet essential requirements of physical health and safety and unable to make informed decisions about matters related to their care. ▪ There is a stronger requirement for counsel for the person "Unless the respondent is represented by counsel, the court shall immediately appoint counsel for the respondent" paid through the state if the person is indigent. The non-ID/DD statute allows a person to knowingly waive counsel. ▪ The person will be present at the hearing, except that "the court may exclude the respondent from such portions of the hearing at which testimony is given which the court determines would be seriously detrimental to his or her emotional or mental condition."

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	▪ The statute uses a "clear and convincing evidence" standard of proof. ▪ Neither plenary nor limited guardians can: (1) admit the person to a mental institution, except under specific provisions of law at 17a; (b) admit the person to any "training school or other facility provided for the care and training of persons with intellectual disability" if there is a conflict between the guardian and the protected person, or their next of kin; (c) sterilize the person, perform "psychosurgery" on the person, terminate the protected person's parental rights, prohibit the person's marriage, or consent on the person's behalf to the removal of an organ, except under specific provisions of law at 17a and 45a; (d) consent to any experimental medical procedure, except under specific circumstances in which the procedure is necessary to preserve the person's life or endorsed by a court, an institutional review board, or the person's physician. ▪ If the person is eligible for Department of Disability Services (DDS) s, a written report or testimony must be provided from a DDS assessment team on the severity of the ID/DD and the specific areas, if any, where supervision and protection of a guardian is needed. ▪ The court is required to review each guardianship at least every three years and shall either continue, modify, or terminate the order of guardianship. Written reports on the condition of guardianship are required on the person's condition, with less mandated reports for people within the severe or profound range of intellectual disability. The person has a right to counsel.
Florida Fla. Stat. Ann. §§ 393.12, 744.3085	▪ Guardian advocates are only appointed for individuals with developmental disabilities. The court considers them a "less restrictive form of guardianship," even though the guardian advocates have the same powers, duties, and responsibilities required of a guardian under chapter 744." ▪ Guardian advocate may be appointed, without an adjudication of incapacity, if the person lacks some, but not all, decision-making capacity to take care of person or property or if the person voluntarily petitioned for appointment. The guardian advocate is qualified to act as a guardian with the same powers, duties, and responsibilities.

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	▪ Restoration of rights procedures are detailed under this subsection, but appear substantially similar to those in other guardianship statutes.
Hawaii Haw. Rev. Stat. Ann. §§ 333F-11	▪ Director of health may be appointed guardian of a person with an intellectual or developmental disability if: (a) there is no other suitable guardian; (b) the person is expected to need treatment in a residential facility; (c) the person was found "incapacitated" as defined in the guardianship statute; (d) the person is intellectually or developmentally disabled.
Idaho Idaho Code Ann § 66-404 et seq.	▪ Determination of the presence of a developmental disability is part of the required findings for appointment of a guardian, but so is the person's "ability to meet essential requirements of physical health or safety and manage financial resources." Additionally, , "developmental disability" is defined in such a way that substantial adaptive functioning services and a continuing need for services are part of the definition. ▪ Institutional commitment proceedings and guardianship appointment procedures are part of the same series of statutes entitled "Treatment and Care of the Developmentally Disabled." ▪ Legislative intent that "the citizens of Idaho who have developmental disabilities are entitled to be diagnosed, cared for, and treated in a manner consistent with their legal rights in a manner no more restrictive than for their protection and the protection of society, for a period no longer than reasonably necessary for diagnosis, care, treatment and protection, and to remain at liberty or be cared for privately except when necessary for their protection or the protection of society." ▪ Evaluation committee must be appointed to evaluate the individual's needs for a guardian and the appropriateness of the potential guardianship. The committee is made up of persons associated with the Idaho Department of Health and Welfare's Bureau of Developmental Disabilities Services. In its report, the committee should state what specific skills the person has and suggest ways to limit the guardian, among other things.
Iowa Iowa Code §§ 222.34 et seq.	▪ Statutory provision states, "if a guardianship is proposed for a person with an intellectual disability, guardianship proceedings shall be initiated and

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	conducted" pursuant to Iowa's standard guardianship statute (Iowa Code § 222.34). ▪ However, "[i]f the court appoints a guardian based upon mental incapacity of the proposed ward because the proposed ward is a person with an intellectual disability . . . the court shall make a separate determination as to the ward's competency to vote. The court shall find a ward incompetent to vote only upon determining that the person lacks sufficient mental capacity to comprehend and exercise the right to vote" (Iowa Code § 633.556(1)).
Kentucky Ky. Rev. Stat. Ann 33 §§ 387.550 to .880	▪ Kentucky's "Guardianship and Conservatorship for Disabled Persons" refers to those who may be appointed a guardian as "having a legal disability." The definition of "developmental disability" from the state's general definitions of "disability" in this statute and uses the federal definition to define the former. However, nowhere else in the statute is the term "developmental disability" used, so it is not statutorily clear how this may impact people with ID/DD. Concerns may be raised that a person with a developmental disability could be presumed to need a guardian. ▪ The Kentucky statute otherwise appears to pertain to all people with disabilities (who do not fall into some other category, such as minors or people under the jurisdiction of Veterans Affairs), rather than specifically people with ID/DD.
Michigan Mich. Comp Laws Ch. 4 330.1600 et seq.	▪ Guardianship of adults with ID/DD can only be appointed under this chapter. ▪ Petition must be accompanied by a report that contains (1) a description of the person's developmental disability, (b) current evaluations of the person's mental, physical, social, and educational condition, adaptive behavior, and social skills, (c) an opinion whether guardianship is needed, the type and scope of the guardianship, and the reasons for the guardianship, (d) a recommendation concerning appropriate rehabilitation and living arrangements, (e) the signatures of those who performed the evaluations, one being a physician or psychologist who is competent in evaluating persons with developmental disabilities, and (f) a list of the person's medications.

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	▪ Appointment requires specific court findings on the record regarding the nature and extent of the person's impairment, the person's capacity to care for himself, the person's ability to manage his financial affairs, and the appropriateness of the proposed living arrangement. ▪ To appoint a guardian there must be a finding on the extent of the person's ability to make and communicate "responsible decisions concerning his or her person." It is not clear from the context what a "responsible decision" would be. ▪ Any limited guardianship established for developmentally disabled persons must be substantially and specifically limited in scope only to the extent necessitated by the individual's actual mental and adaptive limitations. ▪ The probate court needs only give "due consideration" to the individual's preference regarding the person to be appointed guardian, rather than being required to appoint that designee unless he or she is unsuitable or unwilling to serve as guardian.
Minnesota Minn. Stat. §§.252a.01-252a.21.	▪ Allows for the Commissioner of Human Services to be named as public guardian for an individual with a developmental disability if no other person is willing to become the person's guardian. ▪ Whether the individual has a defined developmental disability is relevant to the proceedings. ▪ For people subject to ID/DD guardianship, an annual review of physical, mental, and social adjustment and progress is required. ▪ If the Commissioner determines the person no longer needs public guardianship, the commissioner or local agency shall petition the court to restore capacity and modify the court's previous order. ▪ The person has certain rights including the right to petition the court for termination or modification of the guardianship and to be represented by an attorney in any proceeding. ▪ As public guardian, the commissioner is required to take actions and make decisions on behalf of the person that encourages and allows the maximum level of independent functioning in a manner least restrictive to personal freedom "consistent with the need for supervision and protection" and permit and encourage maximum self-reliance and input by

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
	the person's nearest relative.
New York NY Surr. Ct. Pro. Act Law §§ 1750-1761	▪ Appointments are driven by diagnosis (intellectual disability and developmental disability) rather than function, relying on a finding by health care professionals of the presence of certain developmental disabilities. ▪ A hearing on the guardianship petition is not required in all cases. For guardianship brought by parents, or another person with the consent of the parents, the court may dispense with the hearing. ▪ Where there is a hearing, the person's presence may be more easily dispensed (if "likely to result in physical harm," or the person is "medically incapable" of attendance, or there are "such other circumstances which the court finds would not be in the best interest" of the person). ▪ The burden of proof is lower—unlike the non-ID/DD statute (clear and convincing evidence of three-prong criteria) —and there is no indication of the burden of proof; and as a civil proceeding, it is presumptively preponderance of the evidence. ▪ There is no clear right to counsel. ▪ There is no clear right to cross-examine. ▪ There is no requirement for court findings after a hearing. ▪ There are no provisions for considerations to be taken by the court as to the eligibility and qualification of the guardian to be appointed. ▪ Upon determination of diagnosis and "best interest" finding, no less restrictive alternatives are required to be considered. ▪ Guardianship cannot be limited. ▪ It only requires annual financial reports by a guardian of property. ▪ Guardianship presumptively continues for the life of the person and can be modified to protect the person's "financial situation and/or his or her personal interests" without a hearing. ▪ The decisions of a guardian are based on "best interest." ▪ The guardian can make "any and all health care decisions" for the person with a disability—including those decisions which are typically prohibited by other states unless the person or next of kin directly consents—or is limited to only being authorized under very specific circumstances (such as withholding of life-saving care).

State	Main Distinctions Compared to Non-ID/DD Guardianship Provisions
South Dakota S.D. Cod. Laws 27B-3-1 to 3-52 & 29A-5-110	▪ Allows state institutions for people with developmental disabilities to file a guardianship petition if an individual they are serving cannot consent to being institutionalized. ▪ An employee of the institution *can* be appointed as guardian "if the court finds the appointment is in the best interest of the minor or protected person."

Appendix B: Table of Analysis of NCI Data for States & Guardianship for People with ID/DD

Source of Data: National Core Indicators, Chart Generator 2014-15, National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved from the National Core Indicators website (http://www.nationalcoreindicators.org/charts/) on October 31, 2018 (for 2008 to 2015 data) and January 18, 2018 (for 2015 to 2016 data)

Key: G = Limited Guardianship, Full Guardianship, or Has a Guardian but unable to distinguish level; F = Full Guardianship; DK = Don't Know; N/A = Chart not available; Total Resp. = Total Respondents

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
AL	27% G 26% F 0% DK	23% G 20% F 1% DK	20% G 18% F 1% DK	40% G 39% F 0% DK	23% G 22% F 0% DK	25% G 23% F 1% DK	N/A	22% G 19% F 1% DK	3031	**26% G 24% F 1% DK**
AR	42% G 33% F 0% DK	54% G 35% F 0% DK	54% G 31% F 1% DK	60% G 43% F 0% DK	60% G 45% F 0% DK	62% G 45% F 1% DK	60% G 43% F 1% DK	63% G 44% F 1% DK	3067	**57% G 40% F 1% DK**
AZ	N/A	N/A	N/A	54% G 51% F 2% DK	N/A	56% G 55% F 3% DK	N/A	59% G 53% F 1% DK	1333	**56% G 53% F 2% DK**
CA	N/A	16% G 7% F 5% DK	N/A	25% G 12% F 21% DK	N/A	N/A	31% G 11% F 7% DK	N/A	25304	**24% G 10% F 11% DK**
CO	N/A	N/A	N/A	N/A	N/A	43% G 39% F 0% DK	46% G 46% F 0% DK	47% G 41% F 0% DK	1217	**45% G 42% F 0% DK**
CT	78% G 64% F 0% DK	N/A	N/A	80% G 67% F 0% DK	77% G 67% F 0% DK	79% G 69% F 1% DK	79% G 72% F 0% DK	83% G 75% F 1% DK	2385	**79% G 69% F 0% DK**
DE	29% G 24% F 6% DK	N/A	N/A	N/A	N/A	N/A	14% G 9% F 3% DK	24% G 11% F 3% DK	1060	**22% G 15% F 4% DK**

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
DC	N/A	42% G 14% F 7% DK	N/A	N/A	N/A	37% G 14% F 10% DK	33% G 14% F 36% DK	54% G 17% F 11% DK	1222	**42% G 15% F 16% DK**
FL	N/A	N/A	25% G 20% F 1% DK	27% G 19% F 1% DK	28% G 21% F 1% DK	28% G 20% F 1% DK	29% G 19% F 1% DK	30% G 20% F 1% DK	7381	**28% G 20% F 1% DK**
GA	11% G 9% F 1% DK	14% G 11% F 2% DK	14% G 11% F 1% DK	17% G 14% F 0% DK	17% G 15% F 0% DK	17% G 14% F 0% DK	12% G 11% F 1% DK	16% G 15% F 0% DK	3886	**15% G 13% F 1% DK**
HI	N/A	N/A	N/A	76% G 75% F 1% DK	77% G 76% F 1% DK	70% G 67% F 1% DK	70% G 67% F 1% DK	66% G 64% F 0% DK	2045	**72% G 70% F 1% DK**
IL	74% G 70% F 1% DK	65% G 59% F 1% DK	65% G 61% F 2% DK	65% G 62% F 2% DK	64% G 60% F 1% DK	62% G 57% F 1% DK	64% G 62% F 0% DK	71% G 68% F 0% DK	2950	**66% G 62% F 1% DK**
IN	34% G 29% F 0% DK	N/A	N/A	N/A	51% G 47% F 0% DK	57% G 53% F 1% DK	48% G 41% F 1% DK	52% G 47% F 1% DK	3039	**48% G 43% F 1% DK**
KS	N/A	N/A	N/A	N/A	N/A	66% G 62% F 0% DK	66% G 63% F 2% DK	66% G 64% F 1% DK	1170	**66% G 63% F 1% DK**
KY	75% G 73% F 0% DK	75% G 74% F 0% DK	67% G 65% F 0% DK	63% G 62% F 1% DK	60% G 57% F 1% DK	63% G 60% F 0% DK	59% G 57% F 0% DK	64% G 62% F 0% DK	3581	**66% G 64% F 0% DK**
LA	16% G 13% F 4% DK	19% G 16% F 3% DK	23% G 19% F 3% DK	17% G 16% F 2% DK	14% G 12% F 2% DK	7% G 6% F 0% DK	8% G 8% F 1% DK	13% G 8% F 2% DK	3336	**15% G 12% F 2% DK**
MA	57% G 50% F 1% DK	N/A	N/A	66% G 58% F 0% DK	N/A	58% G 54% F 0% DK	N/A	60% G 56% F 0% DK	2063	**60% G 54% F 0% DK**
MD	N/A	N/A	N/A	N/A	16% G 14% F 2% DK	16% G 13% F 4% DK	N/A	N/A	745	**16% G 14% F 3% DK**
ME	N/A	77% G 74% F 0% DK	77% G 74% F 0% DK	82% G 78% F 0% DK	46% G 21% F 0% DK	72% G 67% F 1% DK	78% G 74% F 0% DK	77% G 71% F 0% DK	2812	**73% G 66% F 0% DK**
MI	N/A	N/A	N/A	72% G 51% F 0% DK	N/A	N/A	73% G 56% F 0% DK	75% G 54% F 0% DK	1255	**73% G 54% F 0% DK**

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
MN	N/A	N/A	N/A	N/A	N/A	87% G 87% F 1% DK	52% G 42% F 28% DK	54% G 0% F 29% DK	1239	**64% G 43% F 19% DK**
MO	82% G 78% F 0% DK	87% G 85% F 0% DK	83% G 80% F 1% DK	83% G 82% F 0% DK	84% G 82% F 1% DK	83% G 80% F 0% DK	85% G 84% F 0% DK	80% G 76% F 0% DK	3656	**83% G 81% F 0% DK**
MS	N/A	N/A	N/A	N/A	16% G 14% F 13% DK	N/A	N/A	20% G 4% F 0% DK	805	**18% G 9% F 7% DK**
NC	63% G 56% F 1% DK	60% G 54% F 1% DK	64% G 56% F 1% DK	66% G 58% F 1% DK	71% G 64% F 0% DK	73% G 66% F 1% DK	68% G 61% F 1% DK	69% G 58% F 0% DK	6794	**67% G 59% F 1% DK**
NH	N/A	N/A	78% G 75% F 0% DK	N/A	72% G 69% F 0% DK	N/A	73% G 70% F 0% DK	N/A	1213	**74% G 71% F 0% DK**
NJ	70% G 64% F 4% DK	68% G 58% F 3% DK	N/A	65% G 51% F 2% DK	63% G 56% F 3% DK	70% G 63% F 1% DK	73% G 67% F 1% DK	N/A	2580	**68% G 60% F 2% DK**
NV	N/A	N/A	N/A	N/A	N/A	N/A	N/A	33% G 29% F 0% DK	400	**33% G 29% F 0% DK**
NY	31% G 28% F 12% DK	29% G 26% F 11% DK	29% G 27% F 11% DK	33% G 29% F 10% DK	35% G 30% F 10% DK	36% G 33% F 6% DK	30% G 25% F 10% DK	35% G 26% F 6% DK	7548	**32% G 28% F 10% DK**
OH	41% G 28% F 2% DK	42% G 29% F 0% DK	49% G 37% F 1% DK	51% G 39% F 1% DK	50% G 35% F 0% DK	46% G 31% F 0% DK	34% G 25% F 0% DK	49% G 30% F 1% DK	3775	**45% G 32% F 1% DK**
OK	62% G 52% F 0% DK	61% G 49% F 0% DK	61% G 49% F 0% DK	N/A	N/A	67% G 61% F 0% DK	58% G 53% F 0% DK	68% G 63% F 0% DK	2995	**63% G 55% F 0% DK**
OR	N/A	N/A	N/A	N/A	16% G 15% F 1% DK	N/A	N/A	N/A	396	**16% G 15% F 1% DK**
PA	12% G 10% F 8% DK	13% G 11% F 8% DK	14% G 13% F 7% DK	13% G 12% F 7% DK	13% G 11% F 7% DK	13% G 12% F 9% DK	14% G 12% F 8% DK	18% G 13% F 6% DK	8571	**14% G 12% F 8% DK**
RI	N/A	N/A	N/A	N/A	N/A	N/A	N/A	26% G 22% F 5% DK	394	**26% G 22% F 5% DK**

State	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Resp. (2008-16)	Annual Mean
SC	7% G 7% F 10% DK	N/A	N/A	9% G 8% F 4% DK	8% G 6% F 13% DK	11% G 8% F 13% DK	9% G 7% F 10% DK	N/A	1942	**9% G 7% F 10% DK**
SD	52% G 49% F 0% DK	N/A	N/A	N/A	N/A	N/A	52% G 49% F 0% DK	68% G 64% F 0% DK	702	**57% G 54% F 0% DK**
TN	N/A	N/A	N/A	N/A	N/A	56% G 44% F 1% DK	58% G 47% F 1% DK	60% G 43% F 1% DK	1308	**58% G 45% F 1% DK**
TX	37% G 34% F 1% DK	35% G 30% F 1% DK	N/A	N/A	39% G 37% F 2% DK	N/A	49% G 43% F 3% DK	N/A	5608	**40% G 36% F 7% DK**
UT	N/A	N/A	N/A	N/A	47% G 37% F 0% DK	46% G 31% F 1% DK	44% G 31% F 2% DK	55% G 36% F 0% DK	1639	**48% G 34% F 1% DK**
VA	N/A	N/A	N/A	N/A	33% G 30% F 1% DK	38% G 34% F 1% DK	38% G 31% F 6% DK	39% G 30% F 2% DK	3094	**37% G 31% F 3% DK**
VT	N/A	N/A	N/A	N/A	N/A	N/A	75% G 71% F 0% DK	77% G 70% F 0% DK	653	**76% G 71% F 0% DK**
WA	N/A	51% G 43% F 1% DK	N/A	47% G 43% F 1% DK	N/A	N/A	N/A	52% G 49% F 0% DK	1519	**50% G 45% F 1% DK**
WI	N/A	N/A	N/A	N/A	84% G 83% F 1% DK	N/A	N/A	48% G 14% F 48% DK	758	**66% G 49% F 25% DK**
WY	59% G 59% F 0% DK	69% LF 66% F 0% DK	N/A	N/A	N/A	N/A	N/A	66% G 62% F 0% DK	1117	**66% G 62% F 0% DK**
Average (state)	**46% G 41% F 2% DK**	**47% G 40% F 2% DK**	**48% G 42% F 2% DK**	**51% G 44% F 3% DK**	**45% G 39% F 2% DK**	**50% G 43% F 2% DK**	**49% G 42% F 4% DK**	**52% G 41% F 3% DK**	**131588**	**49% G 42% F 3% DK**

Appendix C: Additional Tables of Analysis of NCI Data for Guardianship and People with ID/DD

Source of Data: National Core Indicators, Chart Generator 2014-15, National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Retrieved from the National Core Indicators website (http://www.nationalcoreindicators.org/charts/) on October 31, 2018 (for 2008 to 2015 data) and January 18, 2018 (for 2015 to 2016 data)

Key: Y = Limited Guardianship, Full Guardianship, or Has a Guardian but unable to distinguish level; F = Full Guardianship; DK = Don't Know; N/A = Chart not available; Total Resp. = Total Respondents

Table 1: Age & Guardianship Status

Age	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond.	Annual Average
18-34	45% Y 52% N 3% DK	46% Y 52% N 2% DK	51% Y 48% N 2% DK	52% Y 46% N 2% DK	47% Y 50% N 3% DK	51% Y 47% N 2% DK	52% Y 48% N 4% DK	54% Y 42% N 4% DK See Note	403655	**50% Y 48% N 3% DK**
35-54	45% Y 53% N 2% DK	45% Y 53% N 2% DK	47% Y 50% N 2% DK	52% Y 46% N 2% DK	43% Y 54% N 2% DK	49% Y 49% N 2% DK	48% Y 48% N 4% DK	51% Y 46% N 3% DK	10708	**48% Y 50% N 2% DK**
55-74	44% Y 54% N 3% DK	48% Y 51% N 2% DK	49% Y 49% N 2% DK	55% Y 44% N 1% DK	44% Y 55% N 1% DK	49% Y 49% N 1% DK	47% Y 48% N 4% DK	49% Y 47% N 3% DK	24363	**48% Y 50% N 2% DK**
75 +	30% Y 65% N 6% DK	13% Y 79% N 9% DK	15% Y 78% N 7% DK	35% Y 60% N 5% DK	8% Y 87% N 5% DK	22% Y 76% N 2% DK	28% Y 68% N 1% DK	44% Y 52% N 3% DK	785	**24% Y 71% N 5% DK**

Note: 18-22: 58% Y, 38% N, 5% DK (Total Respondents: 1178)
23-34: 53% Y, 43% N, 4% DK (Total Respondents: 5110)

Table 2: Gender & Guardianship Status

Gender	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond.	Annual Average
Male	44% Y 53% N 3% DK	46% Y 52% N 2% DK	49% Y 50% N 2% DK	53% Y 46% N 2% DK	44% Y 53% N 2% DK	50% Y 48% N 2% DK	50% Y 49% N 2% DK	51% Y 45% N 4% DK	65088	**48% Y 50% N 2% DK**

Gender	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond.	Annual Average
Female	46% Y 51% N 2% DK	47% Y 51% N 2% DK	48% Y 50% N 2% DK	54% Y 45% N 2% DK	54% Y 45% N 2% DK	45% Y 52% N 5% DK	49% Y 47% N 4% DK	51% Y 45% N 3% DK	48657	**49% Y 48% N 2% DK**

Table 3: Race/Ethnicity & Guardianship Status

Race/ Ethnicity	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respond	Annual Average
American Indian or Alaska Native	N/A	47% Y 51% N 2% DK	54% Y 41% N 5% DK	71% Y 29% N 0% DK	N/A	83% Y 19% N 5% DK	N/A	69% Y 31% N 0% DK	2128	**65% Y 34% N 3% DK**
Asian	52% Y 35% N 13% DK	0% Y 100% N 0% DK	N/A	57% Y 35% N 8% DK	80% Y 21% N 0% DK	71% Y 29% N 1% DK	56% Y 41% N 4% DK	56% Y 44% N 1% DK	1686	**53% Y 44% N 4% DK**
Black/ African American	38% Y 59% N 3% DK	39% Y 57% N 3% DK	36% Y 61% N 3% DK	44% Y 54% N 2% DK	35% Y 62% N 3% DK	40% Y 57% N 4% DK	38% Y 58% N 4% DK	41% Y 54% N 4% DK	20815	**39% Y 58% N 3% DK**
Pacific Islander	N/A	N/A	N/A	73% Y 26% N 1% DK	72% Y 28% N 0% DK	61% Y 37% N 1% DK	66% Y 33% N 1% DK	63% Y 38% N 0% DK	385	**67% Y 32% N 1% DK**
White	48% Y 50% N 2% DK	50% Y 48% N 2% DK	51% Y 48% N 2% DK	55% Y 43% N 2% DK	48% Y 51% N 2% DK	52% Y 46% N 1% DK	51% Y 45% N 4% DK	54% Y 43% N 3% DK	80067	**51% Y 46% N 2% DK**
Hispanic/Latino	45% Y 51% N 5% DK	23% Y 70% N 7% DK	34% Y 57% N 9% DK	47% Y 48% N 5% DK	49% Y 47% N 5% DK	47% Y 50% N 3% DK	42% Y 54% N 4% DK	39% Y 58% N 3% DK	6704	**41% Y 54% N 5% DK**
Other	51% Y 43% N 10% DK	11% Y 80% N 9% DK	24% Y 63% N 14% DK	39% Y 51% N 10% DK	28% Y 64% N 8% DK	48% Y 48% N 3% DK	33% Y 63% N 4% DK	43% Y 57% N 0% DK	3847	**35% Y 59% N 7% DK**
Two or More Races	N/A	N/A	N/A	76% Y 23% N 1% DK	68% Y 32% N 0% DK	61% Y 37% N 2% DK	35% Y 62% N 3% DK	69% Y 30% N 0% DK	290	**62% Y 37% N 1% DK**

Table 5: Type of Residence & Guardianship Status

Type of Residence	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respondents	Annual Average
Specialized Institutional Facility for Persons with ID/DD	69% Y 27% N 4% DK	64% Y 32% N 3% DK	76% Y 22% N 2% DK	72% Y 24% N 4% DK	71% Y 27% N 2% DK	71% Y 27% N 2% DK	N/A (see below)	N/A (see below)	5335	**71% Y 27% N 3% DK**

Type of Residence	2008-09	2009-10	2010-11	2011-12	2012-13	2013-14	2014-15	2015-16	Total Respondents	Annual Average
Nursing Facility	24% Y 73% N 3% DK	28% Y 64% N 8% DK	26% Y 59% N 15% DK	34% Y 60% N 6% DK	20% Y 81% N 0% DK	38% Y 55% N 7% DK	N/A (see below)	N/A (see below)	210 (PA, VA)	**28% Y 65% N 7% DK**
Institutional Setting (ICF/ID, nursing home, or other institutional setting)	N/A (see above)	N/A (see above)	N/A (see above)	N/A (see above)	N/A (see above)	N/A (see above)	62% Y 33% N 6% DK	64% Y 25% N 11%DK	2892	**63% Y 29% N 9% DK**
Group Home*	51% Y 46% N 3% DK	50% Y 48% N 2% DK	54% Y 45% N 2% K	60% Y 39% N 1% DK	49% Y 49% N 2% DK	54% Y 45% N 2% DK	57% Y 40% N 3% DK	58% Y 39% N 3% DK	31807	**54% Y 44% N 2% DK**
Agency-Operated Apartment Type Setting	37% Y 62% N 1% DK	47% Y 52% N 2% DK	40% Y 57% N 2% DK	52% Y 46% N 2% DK	37% Y 59% N 4% DK	51% Y 48% N 1% DK	N/A	N/A	3804	**44% Y 54% N 2% DK**
Independent Home/Apartment**	22% Y 77% N 1% DK	28% Y 71% N 1% DK	29% Y 70% N 1% DK	31% Y 68% N 1% DK	25% Y 74% N 1% DK	28% Y 71% N 1% DK	28% Y 69% N 4% DK	34% Y 64% N 2% DK	16949	**28% Y 71% N 2% DK**
Parent/Relative's Home	41% Y 56% N 3% DK	33% Y 64% N 3% DK	46% Y 52% N 2% DK	49% Y 50% N 2% DK	46% Y 52% N 2% DK	48% Y 50% N 3% DK	49% Y 47% N 4% DK	54% Y 43% N 4% DK	39914	**46% Y 52% N 2% DK**
Foster Care/Host Home	48% Y 49% N 3% DK	46% Y 51% N 3% DK	55% Y 44% N 2% DK	55% Y 43% N 2% DK	53% Y 46% N 0% DK	61% Y 39% N 0% DK	54% Y 44% N 2% DK	57% Y 40% N 3% DK	5818	**54% Y 45% N 2% DK**
Other	40% Y 55% N 4% DK	52% Y 43% N 6% DK	58% Y 40% N 2% DK	49% Y 45% N 6% DK	36% Y 59% N 5% DK	50% Y 46% N 4% DK	20% Y 66% N 15%DK	N/A	2461	**44% Y 51% N 6% DK**

* Referred to as a "Community-based residence/group home" in 2014-15 and "Group residential setting (group home)" in 2015-16.

** Referred to as "own home or apartment" in 2015-16.

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