

Roads to Freedom Center for Independent Living (RTFCIL) of North Central PA

Policy Position: Adult Guardianship

Adult guardianship is a problematic system for disabled people. This system was created to help and protect people; however, facts show it is easily misused or abused, and harms disabled people in a variety of ways. As a Center for Independent Living, we recognize these harms and support federal, state and local law and policy reforms that limit the scope and minimize the use of guardianships, protect and restore individual rights, and favor alternatives to guardianship like advance directives and supported decision making.

Adult guardianship is a legal process which affects many disabled people.

Adult guardianship is the process through which an adult is found legally incapable of making decisions and another adult is appointed by a judge to make decisions for them. This process often happens to disabled adults, particularly those with intellectual, developmental, or mental health disabilities, and elders, whose capacity has been questioned or presumed to be lacking. The vast majority of guardianships are full guardianships, in which guardians have full decision-making powers over the individual under guardianship.¹ An estimated 1.5 million people are under legal guardianship nationwide, and that number is increasing.² Guardianships are decreed when a Judge determines that a person with a disability has little or no community resources to allow the person the right to make choices, have control in their decisions and live interdependently in their communities. The Judge's determination can be based on information or the lack of information that is given to them by different sources like family, friends, and representatives of community agencies.

Guardianship is incompatible with the independent living philosophy.

Guardianship is based on the assumption that disabled people cannot make decisions for ourselves. Meanwhile, the independent living (IL) movement says that dependence is created by society's failure to accommodate disability. The Rehabilitation Act of 1973 affirms that independent living programs shall be carried out consistent with principles such as "respect for individual dignity, personal responsibility, self-determination..." and "inclusion, integration, and full participation of the individuals..."³ To the extent that guardianship limits our dignity, personal responsibility, self-determination, participation, or control over our own lives, it is incompatible with the independent living philosophy, and with the IL mission.

"We believe people with disabilities should be able to make their own choices and have control -- to be able to live the lives they want to lead as independently as possible, with the needed accommodations and supports to do so." Erica McFadden, Director for the Office of Independent Living Programs, Administration for Community Living.

We support and promote consumer control through not only alternatives to guardianship but more importantly the use of Person-Centered Plans and partnerships with protection & advocacy (P&A) agencies.

Guardianship removes self-determination and rights.

The power to make all kinds of decisions is stripped away by guardianship. These include many personal decisions about things like marriage, divorce, raising children, who to communicate with and when, where to live, and how to spend money. In some cases, guardianship actually removes a person's right to make a decision. Two rights which are removed by guardianship are the right to make decisions about healthcare, and the right to vote.

People under guardianship lose the right to decide what medical treatment they will get or refuse. Even well-intentioned guardians do not always make decisions in the best interests of the person under guardianship out of fear or misunderstanding. This can harm the person under guardianship. For example, a guardian may forego scheduling cancer screenings for the person under guardianship for fear a test will upset them. The person under guardianship may go untreated for a serious illness. When it comes to life-or-death decisions, the impact of a guardian's misguided feelings would be even greater. This does not deter people from seeking more power to make decisions for others in life-or-death situations. In alignment with the National Council on Independent Living, we oppose any relaxing of legal constraints on the power of guardians to withhold or withdraw life-sustaining treatment from disabled people.⁴

Persons under guardianship are prevented from participating in the democratic process because they lose the right to vote. Some people argue that denying the right to vote to disabled people protects the integrity of the electoral process because giving ballots to allegedly incapacitated people creates the opportunity for third parties to commit voter fraud. However, fear of voter fraud can never be allowed to justify removing someone's right to vote. Other people argue there should be a standard for preserving someone's right to vote, like a test on what an election is about or who is running in an election. This is unfair because no other American is tested on their knowledge of an election, and many people are uninformed. Furthermore, standards like this would likely be discriminatory and applied inconsistently.⁵ Rather than focusing on whether individuals know the names of candidates or might cast an irrational vote, voter protections need to be strengthened to ensure disabled people have equal access to cast a private, independent vote, and that polling places and procedures are accessible.

Guardianship Causes Isolation and Abuse

People under guardianship likely experience a "negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being."⁶ One negative impact of guardianship is isolation. Persons under guardianship do not get to decide who they visit, communicate with, or interact with and when. The resulting isolation can create an environment ripe for abuse or neglect. Some States are beginning to recognize a person under guardianship's right to community and visitation.⁷ However, what the law says does not always happen in practice. One example of this is disabled people being prevented from talking to reporters despite indicating a desire to and having the right to community and visitation.⁸

The harm of guardianship also rises to the level of abuse. The principle behind guardianship is that a person who cannot take responsibility for their own care should have someone else looking out for their interests, but there have been numerous cases of persons under guardianship being subject to abuse *by their guardians*. In a 2010 report, the Government Accountability Office identified hundreds of allegations of physical abuse, neglect, and financial exploitation by guardians in 45 States and the District of Columbia between 1999 and 2010.⁹ The abuse of elders under guardianship in particular has been addressed in the media recently.¹⁰ There are many stories of abuse being committed by guardians across the country.¹¹

Financial exploitation is a common form of abuse.¹² Guardians collect exorbitant fees for service to their clients, but do nothing to look after their interests. Often, persons under guardianship are institutionalized and their assets are sold, sometimes without their knowledge.¹³ People who are already in institutions are at risk of coercion and abuse by the institutions; institutions will petition for guardianship of individuals to ensure they pay their bills.¹⁴ Individuals who do not have friends or family members to serve as a private guardian and are appointed a public guardian are in particular danger of not receiving needed services, being harmed by third parties, or being inappropriately institutionalized.¹⁵ The ongoing theft, institutionalization, harm, and abuse of people under guardianship makes it clear that disabled people continue to be deprived of their lives, liberty, and property, which are protected by the Constitution.

Despite the harms described above, some people try to expand guardianship in order to exercise convenient control over others. For example, the State of California has considered bills that would expand conservatorship as part of an effort to connect homeless people with significant mental health disabilities with services. However, the bills are based on no connection between expanding conservatorship and helping disabled people to move away from homelessness and toward health and financial stability.¹⁶ The bills would expand the definition of who could be subject to involuntary treatment in an institution. The threat of further institutionalization is a threat to the IL mission because institutionalization is the opposite of community integration and participation.

Oversight Has Not Been Effective

Meanwhile, courts are failing to protect people from this abuse for a number of reasons. These include poorly educated judges, lack of background checks of potential guardians, and failure to follow due process. Additionally, many states do not track the number of people subject to guardianship, their demographics, the type of guardian or guardianship they have, and other basic data, or do not provide enough funding for tracking or oversight efforts.¹⁷ Statutory oversight requirements have been strengthened over time, but face many problems in practice.¹⁸ Meanwhile, disabled people continue to be harmed.

Vigorous monitoring efforts by stakeholders must be supported to prevent future abuses of those under guardianship.¹⁹ Furthermore, improved data gathering and tracking would be useful for understanding the outcome of different types of guardianships and the demographics of persons under guardianships. Knowing more about the type of people at risk of and under guardianship will help create effective diversion programs.

Limited Guardianships are Preferred, but are Not a Solution

Realizing the overuse and misuse of full guardianships, States have made changes to their laws to limit guardianships in various ways beyond monitoring. In 2015 alone there were 33 changes in laws on adult guardianship in 18 states and these changes included not only improved monitoring of guardianships, but the rights of persons under guardianship.²⁰ Some States have “Wards Bills of Rights.” Others enumerate rights such as the right to community, to have visitors, or make phone calls.²¹ Many have created some form of a requirement to use a “least restrictive alternative” (LRA) before imposing guardianships, or create an opportunity to tailor limited guardianships to individuals.²²

However, there are reasons to believe that statutory restrictions do not adequately support disabled people’s rights. Disabled people are routinely denied due process in guardianship proceedings because judges do not feel the disabled person needs to be present, or it is too inconvenient to have them present. The determination of capacity can be made without sufficient evidence or without supports in place.²³ If capacity is not adequately assessed, any tailoring will be inappropriate. Weak protections do not mean much in reality. For example, Kansas requires

that a guardian should consider a ward's preferences when making decisions on their behalf, but does not require the guardian to act in accordance with those preferences.²⁴ Furthermore, some States still do not have laws for tailoring guardianships. For example, NY's Olmstead plan recommended in 2013 the state's 17A guardianship law be reformed, in part because those guardianships are not tailored to a person's "specific deficits." The law remains unchanged.

Additionally, courts do little to enforce LRA requirements.²⁵ Judges still grant full guardianships. Judges may not be educated about the law or disability, or are unwilling to change their behavior. Judges may also read the law narrowly. One notable example is a decision by Judge Brett Kavanaugh in 2007. In *Doe Tarlow v. District of Columbia*, Judge Kavanaugh overturned a decision which said that even if disabled people were considered legally incompetent to make decisions, they were still capable of expressing a choice or preference which should be given weight. Judge Kavanaugh ruled those preferences have no weight at all.

Enhancing protections of persons under guardianship and limiting the scope of guardianships are especially important today. The large "baby boomer" population is approaching an age that puts them at risk of guardianship. Monitoring, education of judges, bills of rights and other statutory protections are positive endeavors. LRA requirements are definitely a step in the right direction.

At the same time, it is critical to be aware of the flaws of guardianship that remain. Once guardianships are in place, it is very difficult to restore rights, and restoration does not happen often.²⁶ Guardianship should be seen as a tool of last resort, and those at risk should be diverted to other decision-making tools.

Among the recommendations of last year's Fourth National Guardianship Summit - Maximizing Autonomy and Assuring Accountability - was a recommendation that "States should adopt and implement the Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act (Uniform Act) Key provisions of the Uniform Act include:

- (1) prohibit guardianships where less restrictive alternatives would meet an adult's functional needs;
- (2) require specific court findings before certain critical rights (e.g., to marry, vote, choose visitors) are abridged;
- (3) require petitioners to state whether less restrictive alternatives have been tried and justify any failure to do so;
- (4) create mechanisms that adults subject to guardianship and others can use to trigger modification or termination of an order..."

We must respect a persons' self-advocacy for their rights, keeping a person under guardianship when it is not warranted, is false imprisonment. "We have a duty in every case to protect the constitutional rights of the individual who may be deprived of his or her liberty and autonomy. Courts need the information and tools to prevent abuse and exploitation, and to assure that we do not appoint as guardians anyone who could or would exploit the incapacitated individual," states Judge Lois Murphy, of Montgomery County, PA.

Other Tools Can Help in Decision-Making

There a number of legal tools available to help accommodate a disability or provide assistance in decision-making. These tools include banking services, powers of attorney, durable powers of attorney, health care advance directives, representative payees, medical proxies, and revocable, irrevocable, and special needs trusts. The use of these tools are encouraged and in many cases may avoid the use of guardianship altogether. Even nondisabled people can use these tools to protect their wishes and rights should a disability affect their decision-making in the future. Numerous resources exist to help people use these tools, such as the Promoting Options Less

Restrictive than Guardianship from the American Bar Association and the Lighting The Way to Guardianship and Other Decision-Making Alternatives manual from the Florida Developmental Disabilities Council.

Supported Decision-Making is a Preferred Alternative to Guardianship

The fundamental problem with guardianship is that disabled people are often incorrectly seen as incapable of making their own decisions. Supported decision-making is a tool that can allow an individual to live with their independence intact but still receive assistance. Supported decision making may be informal or formal. Informal supported decision making happens all the time, and is practiced by everyone, disabled and nondisabled alike. In a supported decision-making agreement, a disabled person selects supporters. Supporters help the person understand their options, responsibilities, and consequences. Notably, this interactive process allows the disabled person to practice decision-making skills and expand their capacity for independent choices.

There are excellent resources available to educate people on the process.²⁷

The benefits of using supported decision making are profound. Disabled people retain their rights because there is no court decision. They retain full control over their decisions, and get to direct how assistance is delivered. Self-determination is not just possible but encouraged. People with greater self-determination are healthier, more independent, more well-adjusted, and better able to recognize and resist abuse.²⁸ Like nondisabled people, disabled people get to make choices, even poor choices, and learn from their experiences and mistakes.

The benefits of supported decision making are being recognized by courts and are used to prevent guardianships. One example comes from New York, where a judge found that “there is now a system of supported decision making in place that constitutes a less restrictive alternative to the Draconian loss of liberty entailed by a plenary 17-A guardianship.”²⁹ At the same time, there is a dearth of knowledge of and lack of access to the supported decision-making option, and little emphasis is placed on developing children’s decision-making skills before they reach the age of majority and are at risk of guardianship. Even with the use of person-centered planning, the use of preferences is superficial and there is a bias toward substitute or surrogate decision making.³⁰

We support partnerships that expand the use of supported decision making. Families of young children with intellectual or developmental disabilities need to be engaged on this topic early. Individuals who could serve as facilitators in supported decision making should be referred for training with supported decision-making projects. Educators and service providers should be educated on the benefits of supported decision making so they can inform their clients and divert children from unnecessary guardianships. In nursing home diversion and transition efforts, supported decision making is a valuable tool, given reports of cognitive decline during nursing facility stays. Even individuals currently under guardianship can be referred for legal help with restoration of rights. Engaging in supported decision making prior to going to court can be useful in making their case for restoration of their rights.

Efforts to recognize supported decision-making in law as well as policy must be supported. There is already some progress in this area. Supported decision making is specifically mentioned as a less restrictive alternative in the Uniform Guardianship and Protected Proceedings Act, which State legislatures can adopt. A couple States have also developed their own supported decision-making laws.³¹ Laws that require least restrictive alternatives, particularly supported decision making, before guardianship can be considered should be supported. The Autistic Self Advocacy Network has a model law on supported decision making in the healthcare decision making context. Legal recognition of this decision-making method is critical to ensuring disabled peoples’ decisions are respected.

Guardianship is a deeply embedded legal system that has proven to be incredibly harmful to the Disability Community. There are ways of limiting guardianship's negative impacts, protecting individual rights, and using alternatives that value choice, self-determination, and decision-making by disabled people in their own lives. We support these efforts to ensure independent living for all and call for immediate restoration of the rights of individuals wrongfully placed under guardianship.

The majority of this document was written by the Center for Disability Rights, Inc. (CDR) adopted and updated by Roads to Freedom Center for Independent (RTFCIL) of North Central PA. Both agencies are disability led, non-profit service and disability justice organizations devoted to the full integration, independence and civil rights of people of all ages with all types of disabilities. We appreciate the work that they have done so that other independent living centers might use this paper to write their own policy on guardianship.

September 2022

Endnotes

- ¹ Booth Glenn, Kristin. *Clearinghouse Community*. The Perils of Guardianship and the Promise of Supported Decision Making. (May-Jun 2014) at <http://povertylaw.org/clearinghouse/articles/guardianship>. See also Jameson, J. Matt, Tim Riesen, Shambly Polychronis. *Research and practice for Persons with Severe Disabilities*. Guardianship and the Potential of Supported Decision Making With Individuals With Disabilities. (Jun 2015) <http://journals.sagepub.com/doi/pdf/10.1177/1540796915586189>.
- ² Uekert, Brenda B. & Richard Van Duizend. *National Center for State Courts*. Adult Guardianships: A ‘Best Guess’ National Estimate and the Momentum for Reform. (2011) <https://www.ncsc.org/sitecore/content/microsites/future-trends-2011/home/Special-Programs/4-3-Adult-Guardianships.aspx>.
- ³ Rehabilitation Act of 1973. Title VII Ch. 1.
- ⁴ National Council on Independent Living. Legislative & Advocacy Priorities Guide. (2018) <https://www.ncil.org/wp-content/uploads/2018/03/Policy-Priorities-February-2018.pdf>.
- ⁵ Vasilogambros, Matt. *Governing*. Using Hazy Laws, States Revoke Thousands of Mentally Ill People’s Voting Rights (Mar 2018) <http://www.governing.com/topics/politics/sl-incompetence-mentally-ill-voter-right-states.html>.
- ⁶ Wright, JL. *Int J L Psychiatry*. Guardianship for your own good : improving the well-being of respondents and wards in the USA (2010) p. 354 <https://www.ncbi.nlm.nih.gov/pubmed/21030089>.
- ⁷ American bar Association, *Commission on Law and Aging*, Legislative Fact Sheet: Guardianship and the Right to Visitation, Communication, and Interaction (May 2018) at https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-05-24-visitation-legislative-factsheet.authcheckdam.pdf.
- ⁸ Serres, Chris. *Star Tribune*. Protecting the vulnerable vs. civil rights. (Nov 2015) <http://www.startribune.com/protecting-the-vulnerable-vs-civil-rights/340341182/#/>.
- ⁹ U.S. Government Accountability Office. *Reports and Testimonies*. Guardianships: Cases of Financial Exploitation, neglect, and Abuse of Seniors. (Oct. 2010) <https://www.gao.gov/products/GAO-10-1046>.
- ¹⁰ Last Week Tonight with John Oliver, *Youtube*, “Guardianship” (June 3, 2018) at <https://www.youtube.com/watch?v=nG2pEffLEJo> and Garland, Sarah. *New York Times*. Calls for Court Reform as Legal Guardians Abuse older Adults (Jul 2017) <https://www.nytimes.com/2017/07/28/business/calls-for-court-reform-as-legal-guardians-abuse-older-adults.html>.
- ¹¹ Gurnon, Emily. *next avenue*. Guardianship in the U.S.: Protection or Exploitation? (May 2016) <https://www.nextavenue.org/guardianship-u-s-protection-exploitation/>.
- ¹² U.S. Government Accountability Office. *Reports and Testimonies*. Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults. (Nov 2016) <https://www.gao.gov/products/GAO-17-33>.
- ¹³ Aviv, Rachel. *The New Yorker*. How the Elderly Lose Their Rights (Oct 2017) <https://www.newyorker.com/magazine/2017/10/09/how-the-elderly-lose-their-rights>.
- ¹⁴ Picchi, Aimee. *CBS News*. How nursing homes collect debts: Seizing guardianship (Jan 2015) <https://www.cbsnews.com/news/how-nursing-homes-collect-debts-seizing-guardianship/>.
- ¹⁵ Teaster, Pamela B. et al. *American Bar Association*. Wards of the State: A National Study of Public Guardianship (Apr 2005) https://www.americanbar.org/content/dam/aba/administrative/law_aging/wardofstatefinal.authcheckdam.pdf.
- ¹⁶ Disability Rights Education and Defense Fund, *News*, “Letter of Opposition to Proposed California Legislation to Expand Conservatorship (AB 1971 and AB 2157)” (April 6, 2018), at <https://dredf.org/2018/05/01/letter-of-opposition-to-proposed-california-legislation-to-expand-conservatorship-ab-1971-and-ab-2157/>; Disability Rights California, “AB1971SantiagoMentalHealthInvoluntaryDetentionGravelyDisabledOppose2018May9” (May 9, 2018) at <https://www.disabilityrightsca.org/system/files/file-attachments/AB1971SantiagoMentalHealthInvoluntaryDetentionGravelyDisabledOppose2018May9.pdf>.
- ¹⁷ National Council on Disability. Beyond Guardianship: Toward Alternatives That Promote Greater Self Self-Determination (Mar 2018)

https://ncd.gov/sites/default/files/NCD_Guardianship_Report_Accessible.pdf p. 18; U.S> Government Accountability Office. *Reports and Testimonies*. Guardianships: Coordination Needed to protect Incapacitated Elderly People (Jul 2004) <https://www.gao.gov/products/GAO-04-655>, U.S> Government Accountability Office. *Reports and Testimonies*. Elder Abuse: The Extent of Abuse by Guardians Is Unknown, but Some Measures Exist to Help Protect Older Adults (Nov 2016) <https://www.gao.gov/products/GAO-17-33>.

¹⁸ Karp, Naomi. AARP. Guardianship Monitoring: A National Survey of Court Practices (Jun 2006) https://www.aarp.org/money/estate-planning/info-2006/2006_14_guardianship.html.

¹⁹ Gurnon, Emily. *next avenue*. Guardianship Laws: Improving, But Problems Persist (May 2016) <https://www.nextavenue.org/guardianship-laws-improving-problems-persist/>.

²⁰ American Bar Association. *Commission on Law and Aging*. State Adult Guardianship Legislation: Directions of Reform – 2015 (2015) https://www.americanbar.org/content/dam/aba/administrative/law_aging/2015_final_guardianship_legislative_update.authcheckdam.pdf.

²¹ American Bar Association. *Commission on Law and Aging*. Legislative Fact Sheet: Guardianship and the Right to Visitation, Communication, and Interaction

https://www.americanbar.org/content/dam/aba/administrative/law_aging/2018-05-24-visitation-legislative-factsheet.authcheckdam.pdf.

²² American Bar Association. *Commission on Law and Aging*. Least restrictive Alternative References in State Guardianship Statutes. https://www.americanbar.org/content/dam/aba/administrative/law_aging/06-23-2018-lra-chart-final.authcheckdam.pdf.

²³NCD Report pp. 21-22.

²⁴ Kansas Judicial Council. Basic Instruction for Guardians and Conservators.
<http://www.dc18.org/info/forms/Guardian%20and%20Conservator%20Instructions.pdf>.

²⁵ NCD Report p. 23

²⁶NCD Report p. 37

²⁷ Autistic Self Advocacy Network. The Right to Make Choices: New Resource on Supported Decision-Making (Feb 2016) <http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>.

²⁸ Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998).

²⁹ Matter of Dameris L. 956 N.Y.S.2d 848

³⁰ Adapted from American Association on Intellectual and Developmental Disabilities. Guardianship and Decision Making (Sept 2017) <https://aaidd.org/education/education-archive/2017/09/28/default-calendar/guardianship-and-supported-decision-making>.

³¹ Supported Decision-Making New York <http://sdmny.org/for-advocates/sdm-policy-making-successes/>.