

Guardianship Policy Paper

Guardianships are handled by state laws and so are not the same in every case. Guardianships can result in very different circumstances in individual cases. This paper identifies overarching themes of guardianship but may not describe the circumstances of individual guardianships. There are also many aspects of guardianship that could not be covered in this paper due to the breadth of the topic. 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. **RTF, APRIL, The Disability Community?** recognizes these harms and supports law and policy reforms that limit the scope and minimize the use of guardianships, protect, and restore individual rights, and favor supported decision-making or other alternatives to guardianship. 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. Most guardianships are full guardianships, in which guardians have full decision-making powers over the individual under guardianship. An estimated 1.5 million people are under legal guardianship nationwide, and that number is increasing. Guardianship is incompatible with the independent living philosophy. Guardianship assumes that disabled people cannot make decisions for themselves. Meanwhile, the Independent Living (IL) movement says that dependence is created by society's failure to accommodate people with disabilities. The Rehabilitation Act of 1973 states 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..." 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.

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, whom to communicate with and when, where to live, and how to spend money. In many cases, guardianship removes a person's right to make a decision. 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 opposes any relaxing of legal constraints on the power of guardians to withhold or withdraw life-sustaining treatment from a person with a disability. In some states, a person under guardianship is prevented from participating in the democratic process because they often 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. 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." 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. In Pennsylvania, the same entity that serves as the guardian is also the entity that investigates allegations of abuse for this population. Some States are beginning to recognize a person under guardianship's right to community and visitation. 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. 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. There are many stories of abuse being committed by guardians across the country. Financial exploitation is the most common form of abuse. 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. 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. Individuals who do not have friends or family members to serve as private guardians and are appointed public guardians are in danger of not receiving needed services or being inappropriately institutionalized. 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 to exercise convenient control over others. For example, in 2019 the State of California began considering 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. 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 **RTF, APRIL, ?** mission because institutionalization is the opposite of community integration and participation. Oversight Has Not Been Effective as courts are failing to protect people from this abuse for several 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. Statutory oversight requirements have been strengthened over time but face many problems in practice. Meanwhile, disabled people continue to be harmed. Monitoring efforts must be supported to prevent future abuses of those under guardianship.

Improved data gathering and tracking would be useful for understanding the outcome of different types of guardianships and the demographics of persons under guardianship. 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 to 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. Some States have "Wards Bills of Rights." Others enumerate rights such as the right to community, to have visitors, or make phone calls. Many have created some form of a requirement to use a "least restrictive alternative" (LRA) before imposing guardianships or creating an opportunity to tailor limited guardianships to individuals. 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. If capacity is not adequately assessed, any tailoring will be inappropriate. Weak protections do not mean much. 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. 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. 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 that 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 the protection 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 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. Guardianship should be seen as a tool of last resort, and those at risk should be diverted to other decision-making tools.

Other Tools Can Help in Decision-Making

There are other legal tools available to help accommodate a disability or aid 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 is encouraged. A guardianship may be avoided altogether using these other legal means. Even non-disabled people can use these tools to protect their wishes and rights should a disability affect their decision-making in the future. 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. The benefits of using supported decision-making are clear. 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. Like non-disabled 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 guardianship." At the same time, there is a wealth 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. **RTF, APRIL ?** supports 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 the restoration of their rights. 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.