Bill of Rights for Adults with a Guardian

Commentary

In the United States, there is no nationally recognized statement of rights for adults with a guardian. This model Bill of Rights fills that void.

Guardianship reform efforts since the 1980's have focused on ensuring that persons alleged to be incapacitated have due process protections at the initiation of a guardianship. These rights, among others, include the rights to notice of the petition and the hearing on the petition, to be represented by legal counsel, to have a pre-hearing independent review of the need for the guardianship and the appropriateness of the proposed guardian, to be present during the initial hearing, and to participate in the hearing through testimony and cross-examination of witnesses. Most states have imbedded in their statutory provisions all or most of these pre-adjudication rights. States have recognized that these due process rights are essential to ensure fair proceedings before a guardianship is imposed.

While these pre-adjudication rights to a fair hearing are critical, the state statutes have been largely silent on the rights that a person has after the guardianship has been imposed. Until now, only a handful of states have enacted statutory provisions that set out the rights to be protected and respected post-adjudication.

Development of the NGN Bill of Rights

The National Guardianship Network (NGN), a collaboration of thirteen national organizations that advocate for quality guardianship procedures and practices, convened the Fourth National Guardianship Summit in May 2021. Held virtually in conjunction with the Syracuse University College of Law, 125 summit delegates met to review current guardianship policies and practices and to make recommendations for guardianship reform for the next decade. The first among the twenty-two

---

1 Because state terminology varies, the terms “guardian” or “guardianship” are intended to include the court appointment of another individual or entity to make decisions concerning an adult’s personal and/or financial matters.


3 The member organizations of the National Guardianship Network include AARP, ABA Commission on Law and Aging, ABA Section of Real Property, Trust and Estate Law, Advancing States, Alzheimer’s Association, American College of Trust and Estate Counsel, Center for Guardianship Certification, National Academy of Elder Law Attorneys, National Adult Protective Services Association, National Center for State Courts, National Center on Elder Abuse, National College of Probate Judges, National Disability Rights Network and National Guardianship Association.

4 The Fourth National Guardianship Summit: Maximizing Autonomy and Ensuring Accountability | Syracuse University College of Law
recommendations was to convene a task force charged with drafting a model national Bill of Rights for adults with a guardianship.\(^5\)

The first step in convening the recommended task force was to identify the appropriate members. NGN organizations were asked to nominate individuals who were qualified to serve, representing NGN members, national disability and aging organizations, persons at risk of or formerly subject to guardianship, as well as family and professional guardians. Of the more than 30 nominations received, NGN leadership selected the following to serve on the task force:

Sally Hurme, J.D., co-chair, representing the Center for Guardianship Certification
Heather Connors, Ph.D., co-chair, representing the Massachusetts Center for Guardianship Excellence
Nick Close, individual whose rights had been restored
Melinda Coulter, Florida family guardian and former senior court operations consultant to the Florida Supreme Court and a member of Florida WINGS
Kathy Greenlee, J.D., representing ADVancing States and former Assistant Secretary for Aging, Administration for Community Living
Elizabeth Moran, J.D., representing the ABA Commission on Law and Aging
Elizabeth Prideaux, J.D., representing the National Disability Rights Network as Senior Disability Rights Specialist
Ira Saltzman, J.D., Goldfarb Abrandt & Salzman (ret.), Executive Committee of the Elder Law Section of the New York State Bar Association and the co-chair of its Guardianship Committee
Dan Smerken, Washington State Certified Professional Guardian
Larkin Taylor Parker, J.D., representing Disability Rights North Carolina; now Legal Director, Autistic Self Advocacy Network

The task force met virtually for ten two-hour meetings from January to June 2022. All sessions were recorded and transcribed. The members researched existing statements of rights, court decisions addressing individual rights, and academic literature on rights, as well as the United Nations Convention on the Rights of Persons with Disabilities.\(^6\) The National Guardianship Association Statement of Rights

\(^5\) Recommendation 1.1: The National Guardianship Network (NGN) should convene a task force with representatives that include NGN members; national disability and aging organizations; persons currently at risk of or formerly subject to guardianship; and family and professional guardians to develop an enforceable bill of rights. • The bill of rights will identify the rights of adults subject to guardianship for passage by state legislatures, inclusion in court rules and policies, and adopted in state guardianship regulatory, licensing, training, monitoring and reporting requirements, as applicable. Such bill of rights should be in plain language understandable by adults subject to guardianship. • The task force will identify those inherent rights which cannot be restricted, those rights which can be restricted but cannot be delegated, and those rights which can be restricted but only with further due process protections which ensure the decision is consistent with the adult’s preferences and values, regardless of a determination of legal decision-making status or appointment of a guardian. • The task force will consider, but not be limited to, the following specific rights to ensure dignity, privacy, autonomy, and the opportunity to fully participate in all decisions which affect them: marriage, divorce, relationships and association, communication, due process and notice, voting, education, employment, health care (including reproductive health and end of life), place of residence, community integration, free practice of religion, and personal choices.

\(^6\) Convention on the Rights of Persons with Disabilities (CRPD) | United Nations Enable
for Individuals with a Guardianship\textsuperscript{7} and Florida’s statute on rights\textsuperscript{8} served as the basic format, with input from the other state’s statutory language.

**Organizational structure**

Summit recommendation 1.1 directed the task force to categorize rights into three tiers: those rights which are always retained after a guardian is appointed, those personal rights that the court may restrict but cannot be delegated to a guardian, and the rights that may be delegated to the guardian to exercise on behalf of the adult. The tier-one rights are subdivided into groupings of rights that relate to access to justice and the courts, basic human rights, and decision-making rights.

**Rights Retained**

*Access to justice (Rights 1-8):* The group of access to justice rights are the cornerstone to enforcement of all the other rights. Similar to the existing due process rights afforded a person subject to a guardianship proceeding, the adult with a guardian needs to be able to be seen and heard by the court throughout the life of the guardianship and must have an advocate at all stages after adjudication. The access to justice rights a person had prior to the initial hearing remain after the hearing. A finding of incapacity in no way diminishes the right to due process. The adult should be present and participate at all subsequent hearings just the same as the right to be present and participate at the initial hearing.

Because a guardianship may continue for years, or even decades, adults with a guardian should have access to the court to raise any concerns. The summit delegates emphasized the importance of having the court reevaluate the on-going necessity for the guardianship. Recommendation 1.3 asserts that states and courts must ensure full access to a full or partial restoration of rights as soon as possible after a right is legally restricted. Steps addressed by the summit delegates to ensure this right include notice of the right to restoration, meaningful periodic review of the necessity for the guardianship, and legal representation. The Bill of Rights specifies that the adult has the right to let the court know of any concerns and the right to ask the court to review the need to change the guardianship.

It is well understood that everyone’s abilities change over time. The disability that precipitated the need for the appointment of a guardian may get better or worse. The capacity to make a decision may be improved through medical treatment, education, training in decision making skills, rehabilitation, and support. Additionally, the level of capacity needed to make decisions varies depending on the type of decision. A person who may not be able to manage large investments can have the capacity to manage day-to-day financial matters. The criteria for determining testamentary capacity is distinct from the criteria to evaluate the need for a guardianship. Due to these variations over time and decision type, the adult whose capacity is being challenged and whose rights may be restricted has the right to an assessment by a professional who is qualified to evaluate what the adult can do and whether each specific right may be restricted or restored. Bill of Rights #6 reflects Summit Recommendation 1.2: “An impartial, valid, and reliable assessment by a compensated and qualified person...who has knowledge and training about decision-making in the area(s) related to the proceedings.”

Full citizen participation in court proceedings requires supports and accommodations that ensure the adult’s ability to effectively communicate with the court and understand the proceeding. Perfunctory

\textsuperscript{7} Rights-of-Individuals-Under-Guardianship.pdf
\textsuperscript{8} Fla. Stat. § 744.3215.
notice does not protect the due process rights of all citizens. For adults to know what their rights are, their rights must be explained in a way the adult understands, in their preferred method of communication and in the language of their choice.

The summit delegates and the task force members were well-aware of the difficult issues concerning the appointment of counsel and the role of counsel in guardianship proceedings. The key barrier historically to legal representation has been the cost of paying for counsel, both to the state and to the adult’s estate. Nevertheless, the summit recommendations make three specific references to the right to legal representation to provide meaningful due process.

- Recommendations 1.2 and 1.3 each call for “a qualified and compensated lawyer, paid a reasonable fee through the use of public funds if the adult is unable to pay, and appointed by the court should the adult not have a lawyer of their own choosing.”
- Recommendation 3.1, which calls for the adoption of the Uniform Guardianship, Conservatorship and Other Protective Arrangements Act, reiterates the need for appointment of a qualified and compensated lawyer to represent the adult’s expressed wishes in all guardianship proceedings.
- Recommendation 4.3 calls for appropriate funding for advocacy measures to safeguard the rights of adults with a guardian including, among others, “continuing representation by a qualified lawyer appointed at the outset of the case” with the suggestion that the appointment be a legal services, public defender, or other public service lawyer to minimize expenses to the state or estate.

In line with the summit recommendations, Bill of Rights #2 simply states that the adult has the right to a lawyer who advocates for the outcome the adult wants. The ethical responsibility to represent client wishes, rather than some devised formulation of what could be in the client’s best interest, must be honored in all stages of a guardianship proceeding. The distinction between the role of counsel and the role of a guardian ad litem is protected in this bill of rights.

Core Human Rights (Rights 9-15): All adults have basic human rights. Those rights do not disappear following a court’s finding of some level of decisional incapacity. Rights #9 through #15 enumerate those rights all people have and value: to be treated with dignity and respect, to be free from abuse, to be as independent as possible, to have religious freedom, privacy, safe environments, and sexual expression.

Decision-making Rights (Rights 16-21): An adult with a guardian does not lose the right to continue to participate in decisions that are being made on their behalf. It is incumbent on the guardian to respect and advocate for the adult’s goals, needs and preferences when making decisions. Because a court has determined that a guardian is needed to protect the safety and well-being of the adult’s person and property, the guardian’s primary responsibility is to ensure that the adult receives the necessary services that enhance their well-being and provide for their safety. Prudent management of the adult’s resources is essential to provide for the adult’s financial security. The right to decide what matters to keep confidential is the same as it is for those without a guardian.

Rights Restricted

Depending on the adult’s special circumstances, it may be appropriate for the court to restrict some personal rights, but it should do so only when the court has made a specific finding of the necessity to
restrict that specific right. This grouping of rights includes those rights that cannot be delegated to the guardian. These rights are to have a driver’s license, vote, travel, be educated, and be employed. Each of these rights entails a different capacity determination. The need to restrict driving privileges is significantly different than any need to restrict the civil right to vote. The criteria to restrict the right to vote should be no different than for all other citizens; the inability to express a desire to vote. The court needs to give specific approval for any restrictions on the rights to communicate and interact with others, change marital status, be educated or employed, travel, or to maintain reproductive health and procreation.

The access to justice rights that afford due process protections include the right to legal representation at the initiation of the guardianship as well as throughout the life of the guardianship and the right to an assessment of specific capacities, apply when restricting any of the rights in this group.

*Rights Delegated*

The final grouping contains those rights which the court may find it necessary to authorize a guardian to exercise on behalf of the adult. These rights may be delegated to the guardian only after the court’s specific determination that it is necessary for the guardian to make decisions concerning these areas of personal choice for the adult’s safety and well-being and that the decisions the guardian makes are consistent with the adult’s preferences and values. Whether the guardian is making decisions about obtaining needed services, consenting to medical treatment, or determining a place of residence, the adult has the right to participate in those decisions to the greatest extent possible. Decisions delegated to the guardian concerning the legal rights to sue, contract, gift and manage money are to be made consistent with the adult’s preferences and values, and with the adult’s participation to the extent they are able and willing to be involved.

August 2022