INTRODUCTION

One of the more recent pushes in guardianship reform has been the call to protect the post-adjudication rights of those subject to guardianship by, among other methods, the creation of state-based, statutory bills of rights. These statutes affirmatively enshrine in state law the rights retained by those under guardianship, reinforcing the idea that legal personhood is by no means lost when a guardianship is granted. As an additional benefit, the laws also serve to clarify the purpose of the guardianship and the role of the guardian (and in many ways the duty of the court and the obligations of the attorney for the person under guardianship). Such laws are to the benefit of marginalized older adults under guardianship just like they are everyone else. But they also have the potential to more specifically address concerns unique to those who are marginalized.

CALLS FOR REFORM SURROUNDING POST-ADJUDICATION RIGHTS

Although some states had already enacted statutes to protect post-adjudication rights before the Fourth National Guardianship Summit in 2021, the current, broader push for the creation of bills of rights can largely be traced to the recommendations resulting from that summit.1 The delegates recommended that the National Guardianship Network convene a broad-based task force to develop an enforceable bill of rights that could be passed by state legislatures and utilized by courts and others.2 The recommendation directed the task force to consider rights to ensure dignity, privacy, autonomy, and the opportunity to fully participate in decisions, at a
minimum, and to identify rights that (1) cannot be restricted, (2) can be restricted but not delegated, and (3) can be restricted but must be exercised consistent with the adult’s preferences and values.3

CURRENT REFORM EFFORTS SURROUNDING POST-ADJUDICATION RIGHTS

In response to the Fourth National Guardianship Summit’s recommendation, a task force created a new model bill of rights.4 In August 2022, the National Guardianship Association, by board resolution, adopted the newly created model bill of rights into its already existing statement of rights, issuing the new National Guardianship Association Bill of Rights for Adults Who Have a Guardian.5

A number of states already have statutes setting forth the rights of a person subject to guardianship. However, the rights purportedly protected by these statutes, the level of protection contemplated, and the possibility that those rights might be restricted by a court or guardian varies widely from state to state.6

At the federal level, in March 2023, Senator Casey introduced the Guardianship Bill of Rights Act, which, among other things, contemplates the creation of a set of requirements relating to the civil rights of covered individuals under guardianship.7 After its introduction, the bill was referred to the Senate Committee on Health, Education, Labor, and Pensions, where it appears to have stalled.

MARGINALIZED OLDER ADULTS & CULTURAL PROTECTIONS POST-ADJUDICATION

A statute enumerating post-adjudication rights in guardianship is an invaluable legal tool that serves multiple purposes. As a policy statement, it reaffirms the personhood of individuals subject to guardianship and the societal commitment to protecting their rights. It empowers those under guardianship and confirms and guards their ability to make decisions about their own lives. It educates guardians on their duties and obligations and reminds them that their grant of power is limited. It establishes guardrails for the court. And for the attorney representing the person subject to guardianship, it provides the legal “hook” needed to enforce the client’s rights and potentially reach the client’s goals.

For marginalized older adults, a statute protecting post-adjudication rights has the potential to do even more. It has the potential to bring concepts of equity and inclusion into the guardianship system to address at least some of the unique issues faced by marginalized older adults who are otherwise in danger of having their unique identities erased within that system through bias and dismissive othering. Specifically, a statutory bill of rights could – and should – protect older adults’ fundamental right to maintain their unique cultural identity and to participate fully in their cultural life throughout the guardianship.

CULTURE & THE MODEL BILL OF RIGHTS

The new model bill of rights does reference “cultural practices.” Under “decision-making rights,” the person subject to guardianship has “the right to a competent guardian who advocates for [their] goals, needs, and preferences and respects [their] desires, including medical treatment preferences, cultural practices, and religious beliefs.” When it comes to the protection of cultural identity and participation, however, that is not enough. The right to cultural identity and participation should be treated the same way as religious preference, as both a “core human right” retained throughout the guardianship and a “decision-making right.” If the guardian fails to advocate for those preferences, the person subject to guardianship can then seek redress from the court to enforce the core human right and is not left merely with an argument about the guardian’s failure to adequately advocate on the point.
CULTURAL RIGHTS ARE FUNDAMENTAL HUMAN RIGHTS

An individual’s right to engage in cultural life has long been considered a fundamental human right. In 1948, following the atrocities of the Second World War, the United Nations General Assembly adopted the Universal Declaration of Human Rights and its mandate that “[e]veryone has the right freely to participate in the cultural life of the community.”9 That right has been restated in a number of other international instruments,9 as well as in UNESCO’s Universal Declaration on Cultural Diversity, which states, among other things, that “all persons have the right to participate in the cultural life of their choice and conduct their own cultural practices.”10

In 1977, the United States signed the International Covenant on Economic, Social and Cultural Rights, a multilateral treaty adopted by the United Nations General Assembly, which also asserts the substantive right of every person to participate in cultural life.11 Detailed guidance later issued regarding the right defines “cultural life” broadly as encompassing such things as ways of life, language, non-verbal communication, rites and ceremonies, food, clothing, customs and traditions, and more.12 It describes “participation” as, among other things, the right everyone has to choose their own identity and engage in their own cultural practices.13 The guidance also notes the need for special protections of the cultural rights of women, older persons, persons with disabilities, minorities, indigenous peoples, and persons living in poverty.14

Culture is such a fundamental building block of identity that its presence or absence impacts individual mental health and well-being. Research shows that a strong cultural identity and cultural participation provides an individual with a sense of belonging, purpose, social support, and self-worth.15 It can also increase resilience, enhance self-esteem, engender pro-social coping styles, and protect against mental health symptoms.16 It may even buffer the psychological distress caused by discrimination.17

As such, cultural identity, expression, and participation must be protected and enshrined in any statute protecting post-adjudication rights as fundamental, core human rights retained throughout a guardianship. Otherwise, within the guardianship system, there is the real danger that the individual’s cultural identity might be erased and their cultural participation stifled.

Think, for example, of a Native American or Asian American older adult who expresses their desire to age and receive medical treatment according to the “old ways.”18 Or an LGBTQ+ older adult who wants to remain “out of the closet” and part of the LGBTQ+ community as they age. Or an older adult who has lived their entire adult life in the U.S. within an insular, non-English speaking immigrant community who wants to continue living within that culture (with respect to diet, dress, medical care, living arrangements, holidays and celebrations, and the like). For those adults, such choices are foundational to identity. They also intersect with fundamental notions of dignity, respect, independence, and, in some instances, religious freedom and practice.

The guardianship, therefore, needs to respect and actualize these choices and the older adult’s cultural identity. Without this requirement built into statute or bill of rights, a guardian might ignore (or consider and “overrule”) the older adult’s stated desires. This could be prompted by a lack of cultural humility, a fundamental lack of knowledge and understanding, or, more troubling, a prioritization of the guardian’s own convenience and modus operandi above the stated desires of the older adult.

In such a situation, the older adult needs to have the ability to seek meaningful redress to enforce their right to cultural identity and participation, just like they would if there had been a violation of their right to be free from abuse and exploitation. The legal “hook” the older adult needs to accomplish that redress is the inclusion of those rights in a statutory bill of rights with an actionable enforcement mechanism.
RECOMMENDATIONS

• The right of the person subject to guardianship to maintain their cultural identity and cultural participation throughout the entirety of the guardianship should be included in any state bill of rights and in the model bill of rights as a core human right that cannot be restricted or delegated.

• States should enact the model bill of rights, at a minimum, with the addition of the right to maintain cultural identity and cultural participation as a core human right. States that have already enacted a bill of rights should amend the state statute to include the right to maintain cultural identity and cultural participation as a core human right.

• The Uniform Guardianship, Conservatorship, and Other Protective Arrangements Act should be revised to include the model bill of rights with the addition of the right to maintain cultural identity and cultural participation as a core human right.

• Courts should state the right of the person subject to guardianship to maintain cultural identity and cultural participation in any order establishing a guardianship.

• Courts should require training for all guardians on the maintenance of cultural identity and cultural participation, including the concepts of cultural competence and cultural humility.

CONCLUSION

The issues raised in this series and the recommendations offered are not exhaustive and probably point only to the tip of what is likely a very large iceberg. The hope and goal, though, is that a discussion of these issues will lift up and advance a larger dialogue about equity and inclusion in the guardianship system, especially surrounding marginalized older adults. Seemingly more than any other area of ongoing legal reform, and to the credit of all involved, guardianship reform has focused on and upheld the value of personhood. Personhood is intertwined with identity, and identity is intertwined with culture, race, ethnicity. As we work to transform the guardianship system, all of those concepts must be placed in the foreground, and equity must be baked into guardianship reform efforts. Equity as an afterthought or something discussed around the edges will never succeed in appreciably moving the needle toward the elimination of the disparities and bias faced by marginalized communities within the larger guardianship system so that meaningful reform equally benefits all.
ENDNOTES

1. At the 2021 summit, the delegates’ work regarding the protection of post-adjudication rights was largely informed by an article authored by Edwin Boyer and Rebecca Morgan. See Edwin M. Boyer & Rebecca C. Morgan, Maximizing Autonomy and Ensuring Accountability Rights-Based Post-Appointment Issues in the “New Normal,” 72 Syracuse L. Rev. 41, 45-47 (2022). The authors sorted the already enacted state bills of rights into two groups: those that contained a statement of explicit rights and those that were more implicit, basically statements of retained constitutional and civil rights. See id. at 46. For any statutory protection to be meaningful, the authors noted, the parties would need to know about it, it would need to include “critical and constitutional rights,” and it would need to have an enforcement mechanism, also known to the parties. See id.


3. See id.

4. National Guardianship Network, Bill of Rights for Adults with a Guardian, Commentary (2022), available at https://www.guardianship.org/wp-content/uploads/NGN-Bill-of-Rights-Commentary-8-15-2022-1.pdf#:~:text=5%20Recommendation%201.1%3A%20The%20National%20Guardianship%20Network%202019%20Bill%20of%20Rights%20and%20Personal%20Choices. The 37 rights protected under the model bill of rights are divided into three tiers: (1) rights that are always retained after a guardian is appointed, (2) rights that the court can restrict but not delegate to the guardian, and (3) rights that can be delegated to the guardian. See id. The 21 rights always retained by the person subject to guardianship are further subdivided into three subgroups relating to (1) access to justice, (2) core human rights, and (3) decision-making rights. See id. The “access to justice rights” (rights 1 to 8) relate to due process protections and the ability to seek redress from the court. The “core human rights” (rights 9 to 15), include “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.” Id. The “decision-making rights” (rights 16 to 21) enumerate the rights of the person subject to guardianship to “continue to participate in decisions that are being made on their behalf.” Id. Throughout, the guardian is directed to respect and advocate for the adult’s goals and preferences when making decisions (although the right to participate in decisions ultimately seems to give way to the guardian’s authority to make decisions about safety and well-being). See id.


6. Accompanying the Boyer and Morgan article is an appendix that divides state statutes into (1) those that have an enumerated list of rights, (2) those that list procedural due process rights, and (3) those that clarify the retention of all rights except as limited by guardianship. The appendix is available at https://lawreview.syr.edu/wp-content/uploads/2022/06/Appendix-A.pdf.


See Comment 21, supra note 11, at 2-4.

See id.

See id. at 7-10.


