

VIA ELECTRONIC SUBMISSION (<https://www.regulations.gov>)

August 15, 2023

The Honorable Alison Barkoff  
Acting Administrator and Assistant Secretary for Aging  
Administration for Community Living  
U.S. Department of Health and Human Services  
Attention: ACL-AA17-P  
330 C Street SW  
Washington, DC 20201

Re: Older Americans Act Implementing Regulations, Notice of Proposed Rulemaking  
(RIN 0985-AA17)

Dear Acting Administrator and Assistant Secretary Barkoff:

Thank you for the opportunity to provide comments to the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS), on its Notice of Proposed Rulemaking (NPRM) that seeks to modernize the implementing regulations of the Older Americans Act of 1965 (OAA). The undersigned organizations offer the following comments, which are focused on the OAA NPRM provisions that address guardianship and alternatives.

We applaud ACL for recognizing the importance of advancing less-restrictive alternatives to guardianship for older adults through its OAA grants and allotment programs. As highlighted in the 2018 report of the National Council on Disability (NCD), while guardianship systems are embedded in state law, they implicate critical constitutional and federal civil rights, including those under the Americans with Disabilities Act (ADA). Guardianship must be understood as a disability rights issue, regardless of whether it impacts older adults. Virtually every person under guardianship or at risk of guardianship either has – or is being perceived as having – a disability that substantially limits their ability to manage their own affairs, and thus is protected by federal disability rights laws.<sup>1</sup> We also appreciate that the OAA NPRM incorporates specific reference to Supported Decision-Making, which is an important way to promote and support the rights and self-determination of older adults as they age<sup>2</sup> and is gaining traction across the United States. We offer several suggestions for further refining these regulations to ensure the intent of this rulemaking with respect to advancing less-restrictive decisional supports can be fully realized.

## I. DEFINING “DEFENSE OF GUARDIANSHIP”

Under Section 307(a)(11)(E) of the OAA, area agencies on aging (AAAs) are required to prioritize providing legal assistance to older people in “defense of guardianship.”<sup>3</sup> We greatly appreciate ACL providing clarification to AAAs about what “defense of guardianship” means –

---

<sup>1</sup> See NAT’L COUNCIL ON DISABILITY, *Beyond Guardianship: Towards Alternatives That Promote Greater Self-Determination*, 41-42 (March 2018), <https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives>; *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. COLO. L. REV. 157 (2010).

<sup>2</sup> See Morgan K. Whitlatch & Rebekah Diller, *Supported Decision-Making: Potential and Challenges for Older Persons*, 72 SYRACUSE L. REV. 165 (2022), <https://lawreview.syr.edu/wp-content/uploads/2022/10/5.-Whitlatch-Diller.pdf>.

<sup>3</sup> 42 U.S.C. 3027(a)(11)(E).

namely defending older adults against guardianship by diverting them towards less restrictive options, opposing appointment of a guardian in favor of less restrictive decisional supports, and seeking limitation or revocation of guardianship.<sup>4</sup> Based on our experiences with the AAA network, this clarification is much needed to ensure consistency in interpretation. We recommend that ACL incorporate clear examples of less restrictive options, including Supported Decision-Making, in this definition, as it does later in the OAA NPRM when setting forth the role and responsibilities of Legal Assistance Developers.<sup>5</sup> More specifically, we ask for the following amendments to the **proposed Section 1321.93(d)(1)(ii)** be made to expressly reflect the intent stated in the OAA NPRM preamble.<sup>6</sup>

(ii) Defense of guardianship includes . . . (B) Representation to promote use of least-restrictive alternatives to guardianship, **such as supported decision-making, health care and financial powers of attorney, and advance directives**, to preserve or restore an individual's rights and or autonomy.

## II. LIMITED EXCEPTION ALLOWING FOR REPRESENTATION OF GUARDIANSHIP PETITIONERS

In the OAA NPRM, ACL seeks comments on how to regulatorily reconcile conflicting language within the OAA. The general intent of OAA includes “assist[ing] . . . older people to secure equal opportunity to the full and free enjoyment of . . . freedom, independence, and the free exercise of individual initiative in planning and managing their own lives.”<sup>7</sup> Yet the OAA also states that Title III-B legal services may be used for legal representation “in guardianship proceedings of older individuals who seek to become guardians, if other adequate representation is unavailable in the proceedings.”<sup>8</sup> In the OAA NPRM, ACL states its belief that “legal assistance should not be used to represent a petitioner for guardianship of an older person except in the rarest of circumstances.”<sup>9</sup> To that end, ACL proposes to allow a legal assistance provider to represent a petitioner for imposition of guardianship only if: (1) it is an older individual who is seeking to become the guardian; (2) no other alternatives to guardianship are appropriate; and (3) other adequate representation is unavailable in the proceedings.<sup>10</sup>

We understand that ACL is operating under statutory constraints as to what legal representation it can regulatorily prohibit in this context and that is attempting to strike a balance between conflicting provisions of the OAA. However, we strongly oppose scarce Title III-B funds being used to represent guardianship petitioners, even if only older adult petitioners qualify. Providing such legal assistance creates the strong potential for conflicts of interest within AAAs that undermine the broader purpose of the OAA. Imagine a scenario in which an AAA successfully represents an older petitioner in seeking guardianship over another older person. What

<sup>4</sup> See OAA NPRM Sec. 1321.93(d)(i) and(ii).

<sup>5</sup> See OAA NPRM Sec. 1324.303(4)(ii).

<sup>6</sup> See 88 Fed. Reg. 39,568, at 39,587 (June 16, 2023) (“We interpret this provision to include advice to and representation of proposed protected persons to oppose appointment of a guardian and representation to seek revocation of or limitations of a guardianship. It also includes assistance that diverts individuals from guardianship to less restrictive, more person-directed forms of decision support such as health care and financial powers of attorney, advance directives and supported decision making, whichever tools the client prefers, whenever possible.”).

<sup>7</sup> 42 U.S.C. 3001(10).

<sup>8</sup> 42 U.S.C. 3030d(a)(6)(B)(ii).

<sup>9</sup> See 88 Fed. Reg. at 39,587.

<sup>10</sup> See *id.* at 39,587-39,588.

recourse does the AAA have if the older person under guardianship later comes to the AAA to complain of abuse, neglect, or financial exploitation at the hands of that very guardian? The AAA may well be conflicted out from providing legal assistance against the interests of the petitioner. In addition, over the last decade, ACL has directed more attention and grant funding to recognizing and supporting the dismantling of pipelines to guardianship for people with intellectual or developmental disabilities.<sup>11</sup> Allowing Title III-B funds to be used by AAAs to represent, e.g., “older relative caregivers”<sup>12</sup> in obtaining guardianship over younger adults with disabilities could be seen as working at cross-purposes to other important ACL initiatives.

We firmly believe that OAA funds would be better used in advancing alternatives to guardianship, including Supported Decision-Making, through proactive outreach, training, education, legal representation, and innovative initiatives and projects for older adults, including those that improve access to augmentative and alternative communication (AAC). An estimated 5 million children, teenagers, working age persons, and older adults in the United States cannot rely on speech alone to be heard and understood. Instead, they require AAC tools and supports to express themselves and lead their lives. Strides are being made in law, policy, technology, and understanding that should make accessing AAC routine. Nevertheless, people who require, but are denied, AAC often experience restraint and seclusion, violence, segregation, institutionalization, unnecessary guardianships, and other violations of their rights and liberties.<sup>13</sup> Such individuals are deemed incompetent, stripped of their autonomy, and subjected to guardianship and conservatorships, often simply because no one takes the time nor makes the effort to effectively communicate with them, as well as recognize and affirm the decisions and choices they want and have the right to make for themselves. Supported Decision-Making can disrupt this cycle and should be utilized to protect the civil rights of people with expressive communication disabilities, including those who need but currently lack access to robust, language-based AAC.

If ACL determines an exception to the general OAA NPRM’s prohibition against legal representation of guardianship petitioners remains necessary, we then ask that the exception incorporate prerequisites that require not only exhaustion of other available sources of representation, but also less restrictive options for decisional support. ACL should consider carefully how it will be promoting rigorous monitoring for compliance with such an exception. In addition, we are aware of circumstances in which Title III-B legal service providers have themselves served as guardianship petitioners, without a separate client. Therefore, if ACL decides to keep its proposed exception, we ask that it incorporate additional language, adapted from its preamble,<sup>14</sup> into **proposed Section 1321.93(d)(2)(ii)(A)**:

---

<sup>11</sup> See ADMIN. FOR COMMUNITY LIVING, “Supported Decision Making Program,” <https://acl.gov/programs/consumer-control/supported-decision-making-program> (describing ACL’s five-year grant to the National Resource Center for Supported Decision-making and three one-year planning grants to state-based collaborative); ADMIN. FOR COMMUNITY LIVING, “Protecting Rights and Preventing Abuse of People with Disabilities,” <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems> (describing ACL’s cooperative agreement to support a national Alternatives to Guardianship Youth Resource Center).

<sup>12</sup> See proposed Sec. 1321.81(a)(2)(iii) (definition older relative caregivers age 55 or older who are caring for individuals age 18 to 59 with disabilities and who may be of any relationship, including the biological or adoptive parent).

<sup>13</sup> See, e.g., COMMUNICATIONFIRST, “Research Priorities of AAC Users,” <https://communicationfirst.org/research-priorities-of-aac-users/> (2023).

<sup>14</sup> See 88 Fed. Reg at 39,588 (“A legal service program that would bring guardianship proceedings as part of its normal course of business, that represents a relative of an older person as petitioner at the request of a hospital or nursing facility to seek the appointment of a guardian to make health care

... A legal assistance provider(s) shall not represent a petitioner for imposition of a guardianship except in limited circumstances involving guardianship proceedings of older individuals who seek to become guardians, when no other alternatives to guardianship are appropriate, and only if other adequate representation is unavailable in the proceedings. **A legal assistance program that brings guardianship petitions as part of its normal course of business, or that undertakes representation at the behest of adult protective services, does not meet the requirements of this limited exception.**

### III. CONFLICTS OF INTEREST

We appreciate ACL seeking to promote policies within the OAA network that address individual and organizational conflicts of interest associated with guardianship. See, e.g., OAA NPRM Secs. 1324.21(a)(15) & (c)(2)(x), 1324.303(d)(3)(vi). We support those provisions as written, but we encourage ACL to also consider the inherent conflicts of interests associated with providing legal representation to guardianship petitioners in this context (see Section II above).

### IV. PURPOSE, ROLE, & RESPONSIBILITIES OF LEGAL ASSISTANCE DEVELOPER

We also appreciate that the OAA NRPM expressly requires Legal Assistance Developers to promote activities that enable older adults to access alternatives to guardianship, including Supported Decision-Making.<sup>15</sup> Incorporating into the regulations explicit examples of such alternatives is key to promoting their recognition in this context. Because Supported Decision-Making can be used by older adults not only formally through an agreement, but also informally,<sup>16</sup> we recommend the following amendment to the **proposed Section 1324.303(a)(4)(ii)**:

The Legal Assistance Developer shall also take into consideration promotion of activities that proactively enable older adults and those they designate as decisional supporters through powers of attorney, health care proxies, supported decision making ~~agreements~~, and similar instruments or approaches to be connected to resources and education to manage their finances so as to limit their risk for guardianship, conservatorship, or more restrictive fiduciary proceedings;

---

decisions, or that undertakes representation at the behest of adult protective services would not satisfy our interpretation of the limited applicability of the exception. These parties have access to counsel for representation in petitioning for guardianship.”).

<sup>15</sup> See OAA NPRM Sec. 1324.303(4)(ii).

<sup>16</sup> See Robert Dinerstein, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road from Guardianship to Supported Decision-Making*, 19 HUM. RTS. BRIEF 8, 10 (2012), <https://digitalcommons.wcl.american.edu/cgi/viewcontent.cgi?article=1816&context=hrbrief> (defining SDM as “a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life”); see also SUMMIT DELEGATES, *Fourth National Guardianship Summit: Maximizing Autonomy & Ensuring Accountability – Recommendations Adopted by Summit Delegates*, 72 SYRACUSE L. REV. 29, 30 (2022) (adopting the definition of SDM from the 2012 Dinerstein article).

## V. CONCLUSION

ACL's proposed OAA regulations have the promise of making a fundamental difference in the lives of older adults, including people with disabilities, facing or at risk of overbroad or undue guardianship. While we urge ACL to reconsider allowing scarce Title III-B funds to be used by legal service providers to represent petitioners in seeking guardianship, we appreciate the agency promoting consideration of less restrictive options, including Supported Decision-Making, first, as well as its intention to construe any exception to its general prohibition of such representation narrowly.

Thank you for this opportunity to comment on this important proposed rule. If you have further questions, please contact Morgan Whitlatch at [mwhitlatch@cpr-ma.org](mailto:mwhitlatch@cpr-ma.org).

Sincerely,

Center for Public Representation

CommunicationFIRST

Disability Rights Education & Defense Fund

National Disability Rights Network

Quality Trust for Individuals for Disabilities