



Equity, Opportunity, and Inclusion for People with Disabilities since 1975

TASH POSITION STATEMENT WITH POLICY RECOMMENDATIONS ON GUARDIANSHIP AND ALTERNATIVES, INCLUDING SUPPORTED DECISION-MAKING

STATEMENT OF PURPOSE

TASH affirms the rights of people with disabilities, including individuals with the most significant support needs, to make decisions, to receive the decision-making supports they prefer, and to have opportunities to build their decision-making skills with trusted supporters of their choice. Too often, people with disabilities' access to decision-making supports and opportunities is restricted through informal and formal mechanisms, including guardianship.

Guardianship (known in some jurisdictions as “conservatorship”) is the legal process that transfers important rights from one adult to another. Through guardianship proceedings, courts can restrict the rights of people with disabilities to make life decisions. Too often, those seeking guardianship are unaware of not only the limits of court supervision but also the many ways these restrictions affect persons with disabilities' human rights. People with disabilities under guardianship are too frequently denied these rights, including the rights to visit family and friends, to communicate with people they choose, to attend religious activities, to have privacy, and many others.

Also, many people seeking guardianship are unaware of other, less restrictive ways that persons with disabilities can access decision-making supports. In fact, there are many ways both to protect and to support individuals that are less restrictive than guardianship, even for people with significant support needs. Some people with disabilities who have guardians may be unaware of alternatives that give them greater control over their lives and allow them to receive support to do so.

TASH seeks to build on its [2003 Resolution on Alternatives to Guardianship](#) and its [2021 Resolution In Opposition to Conservatorship / Guardianship](#) to underscore the critical role of decision-making supports in ensuring the basic human right of all people with disabilities, including those with significant support needs, to full and equal participation in all aspects of life. This includes access to individualized and quality decision-making supports that further enable a person with disability to make informed choices as well as to systems that enable persons with disabilities to maximize their autonomy and self-determination. All persons with disabilities are entitled to the presumption of competence, access to the full range of assistive technology and devices, opportunities to develop their self-sufficiency and independence, as well as the pursuit and enjoyment of personal freedom, a range of relationships, the dignity of risk, and decision-making autonomy.

RATIONALE

The United Nations Convention on the Rights of Persons with Disabilities recognizes the basic human right of all people with disabilities to make their own decisions and to access the decision-making supports they prefer. Many U.S. laws, including the Individuals with Disabilities Education Act, the Americans with Disabilities Act, the Rehabilitation Act, the Developmental Disabilities Assistance and Bill of Rights Act, the Medicaid Home and Community-Based Services “Settings Rule” and “Person-Centered Planning Rule,” contain provisions that help to protect this right.

People with disabilities should receive supports that strengthen their autonomy and inclusion. Just as most adults seek decision-making support from doctors, tax advisors, financial advisors, and others, people with disabilities should be given access to chosen, trusted supporters. Support can come in many forms and may include accommodations, such as assistive technology, augmentative alternative communication systems with chosen trained communication partners, customized visuals, and hands-on supports, including opportunities to explore options in order to make an “informed choice”.

Also, decision-making support arrangements made outside of court systems are generally more flexible and empowering, as well as less intrusive, than guardianship. Tools for providing decision-making support without court involvement include powers of attorney for health care, financial, education or other areas, advanced healthcare directives, representative payee arrangements, authorized representative designations, supported decision-making agreements, and more.

Another alternative to guardianship is supported decision-making (SDM). SDM arrangements can be formal or informal and help a person with disabilities to choose trusted supporters to help them explore and understand their choices, make decisions, communicate, implement, and/or act on their own informed choices without loss of rights and dignity, and without court intervention. Informal SDM arrangements may include bringing a friend or relative along to a doctor visit or getting advice on a purchase. Formal SDM arrangements might be set out in a written SDM Agreement (SDMA). A growing number of state laws recognize both informal and formal SDM arrangements.

These alternatives contrast sharply with the guardianship laws and practices in many U.S. states. For example, the National Council on Disability has documented adverse impacts of guardianship including abuse and isolation and described the guardianship system as “broken”.¹ Professionals asked to assess the capacity of adults with disabilities may use traditional clinical assessments that do not account for any supports, including assistive technology devices or support relationships, in their

¹ National Council on Disability, *Turning Rights Into Reality: How Guardianship and Alternatives Impact the Autonomy of People with Intellectual and Developmental Disabilities* (Washington, D.C., June 10, 2019), <https://ncd.gov/publications/2019/turning-rights-into-reality> (accessed March 23, 2023).

assessments. Despite requirements that “least restrictive alternatives” be considered as the primary means to support adults with disabilities, some guardianship hearings last only a few minutes. Furthermore, public guardians, who may not have known the person with disability before the proceeding, may be unfamiliar with the person’s needs, strengths, preferences, and abilities, rarely meet with them, or place them in isolated, congregate settings. Some public guardians are appointed by courts after parents die, even when other family members are identified as successors. When families object to mistreatment or exploitation by public guardians, courts may deny them standing, file restraining orders, and allow the fiduciaries and their attorneys to bill the families for hours they wish to spend opposing the families.

POLICY RECOMMENDATIONS

TASH calls upon government, agencies, and organizations, including protection and advocacy agencies, to protect and defend the rights of adults with disabilities, incentivize and ensure access to supports that make guardianship broadly unnecessary, maximize autonomy for persons with disabilities and to support the principles of self-determination. The purported need for guardianship is more likely evidence of inadequate supports. TASH urges policymakers to:

Improve Data Collection

TASH encourages the federal government and state governments to implement comprehensive and uniform data collection and reporting on guardianship including, but not limited to the type and duration of guardianship, information on guardians and persons under guardianship including their relationship and the primary disability, information on how persons under guardianship receive visitors, and information on how transfer-of-rights policies are implemented.

Increase Awareness and Engagement of School Systems

School systems should implement policies and practices to inform educators, families, and students with disabilities about less restrictive alternatives such as voluntary and individualized supports that may eliminate the perceived need for guardianship.

In states where educational decision-making rights may transfer at the age of majority, school systems should recognize transfer of rights as an opportunity to develop transition plans and to practice youth decision-making skills, including how self-determination, person-centered planning and supported decision-making practices as well as the use of chosen supporters and areas of need can be included in Individualized Education Programs (IEPs).

School systems should provide access to plain language information for transition-age students – including those with intellectual and developmental disabilities and/or who are limited or non-speakers and who use augmentative alternative communication.

Strengthen Safeguards in Guardianship Proceedings

Governments should enforce current provisions of the law to promote restoration of rights through the termination of guardianship and also ensure that persons with disabilities under guardianship have the right to accessible, plain language information on court and guardianship processes, including on their rights to due process and equal protection of law, accessible communication and supports, visitation, choice of guardian, as well as how to report abuse, how to contact a court investigator, how to find advocacy and other support services, and how to exit a guardianship.

Courts should eliminate the requirement for evidentiary hearings where the restoration of rights is uncontested and supported by both the guardian and the person under guardianship and increase the frequency and enforcement of periodic review of guardianships. Background checks of proposed guardians should be mandatory, and guardians should be required to consult with and make decisions aligned with the person's expressed or previously expressed preferences, choices and wishes.

Provide Person-Centered Supports and Accommodations

TASH has identified guidelines and definitions of decision-making supports in the [TASH Position Statement with Policy Recommendations on Community Living](#) that lay the foundation for this Guardianship and Supported Decision-Making Position Statement. The Position Statement on Community Living also clearly outlines accommodations as well as key recommendations to endorse and fund person-centered planning, self-direction, and self-determination and to fund demonstration grants for promoting SDM. Self-advocates, representing persons with disabilities, should have a primary role in the design and implementation of laws, policies and programs related to guardianship and SDM, including efforts to provide and/or lead related training and education.

If an adult with a disability chooses to enter into an SDMA, they should have the choice of one or more trusted supporters. Support may include, but is not limited to, helping the adult with a disability obtain and understand information related to life decisions, communicate decisions to others, and assisting the individual to ensure their preferences and decisions are honored. SDMA should not preclude an adult with a disability from acting independently of the SDMA and the SDMA should not be used by courts or other entities as evidence of incapacity or incompetency.

Increase Federal Support for Supported Decision-Making (SDM)

As TASH states in its Position Statement on Community Living, the federal government has put few resources into SDM. The federal government should fund initiatives to promote SDM and to embed SDM into the Medicaid HCBS system and its person-centered planning rules. We request federal investments in a national demonstration grants initiative of SDM with enough funding to ensure that all interested states receive a baseline of resources to support this work. We also call for the establishment of a

federally-funded Technical Assistance Center to support the provision of requested technical assistance to ensure the implementation of SDM with fidelity at the state level.

TASH stands with other federal and state disability rights advocacy coalitions and organizations in a call to action for guardianship and supported decision-making reforms that strengthen and expand the restoration of rights and the use of flexible, protective, empowering, and voluntary supports that honor the individuality, autonomy, informed choice and preferences, interests and strengths of all persons with disabilities.