Missouri Developmental Disabilities Council
www.MODDCouncil.org
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Self-Determination and Guardianship

The Missouri Developmental Disabilities Council's Position:
Because everyone has the right to make their own choices and direct their lives to the maximum of their abilities, people should not be ordered or kept under guardianship just because they have a disability, need (or want) support, or live (or want to live) in a particular place. People should only be ordered or kept under guardianship when less-restrictive alternatives have failed to help them direct their own lives. Guardianship, when absolutely necessary, should restrict people's rights to the minimum extent possible and empower them to make as many choices as they want and can.

The Missouri Developmental Disabilities Council's Reasons:
Study after study has found that when people with disabilities have more control over their lives – when they have more *self-determination* – they have better lives: they are more likely to be employed, independent, and safer.[1]

Guardianship decreases self-determination because it gives the guardian power to make decisions in place of the ward.[2] People under overbroad or undue guardianship – guardianships that are unnecessary or more restrictive than necessary[3] – can suffer negative life outcomes including decreased health and ability to function.[4] Research has shown that the vast majority of guardianships - over 90%, in one study - authorize the guardian to control all facets of the ward's life.[5] A Congressional subcommittee found "the typical ward has fewer rights than the typical convicted felon."[6]

Today, there are more ways to make more people more independent than ever before. Nevertheless, even though studies find that people with disabilities who did not have guardians were more likely to be employed, live independently, have friends, and be more involved in their communities than those with guardians,[7] the number of people under guardianship has tripled since 1995.[8] Research also shows there is a "school to guardianship pipeline" resulting in increasing numbers of young adults with disabilities being placed in guardianship during or shortly after exiting high school.[9]

Many people with disabilities can manage their own lives without any intervention. For others, there are effective alternatives to guardianship, including Powers of Attorney, Advanced Directives, Representative Payees, ABLE Accounts, Special Needs Trusts, and Supported Decision-Making, that can provide the help they want and need to make their own choices and direct their lives.[10] In addition, a recent study found that young adults who used Supported Decision-Making were more independent and self-confident, became better at making decisions, and made objectively better decisions.[11] Finally, the National Guardianship Association – an organization made up by and for guardians – has stated that alternatives like Supported Decision-Making should be attempted before ordering guardianship.[12]

The Missouri Developmental Disabilities Council's Recommendations:
- As a state and society, we must acknowledge that disability does not equal incapability and respect everyone's right to make their own choices and direct their lives to the maximum of their abilities.
- Educational and training material about alternatives to guardianship, available through Missouri and national organizations, should be provided to people with disabilities and families as well as educational, medical, financial, legal, and other professionals in order to ensure consistency and opportunity across the state.
- Missouri educational, health, and advocacy organizations should develop model forms and practical resources to help people with disabilities and families explore and implement alternatives to guardianship, including Supported Decision-Making, in ways tailored to the user's abilities and interests.
- Missouri should explore enacting legislation or policy requiring schools to provide students and families with information about alternatives to guardianship during special education transition planning, as Virginia did.[13]
- Missouri attorneys, judges, and prospective guardians should receive training to ensure that guardianship proceedings and guardianships are consistent with Missouri Law and (1) protect the rights of people facing guardianship petitions - including their right to be represented by an independent attorney and (2) guarantee that guardianships, when absolutely necessary, only restrict rights to the minimum extent possible and empower wards to make as many decisions as they want and can.
- The Missouri Developmental Disabilities Council, through its work with the National Association of Councils on Developmental Disabilities, should play a lead role in advocating for the U.S. Social Security Administration to recognize and honor Supported Decision-Making and other alternatives to guardianship.

References

1. See, *e.g.*, Karrie A. Shogren *et al.*, *Relationships Between Self-Determination and Postschool Outcomes for Youth with Disabilities*, 4 J. Special Educ. 256 (2015); Michael Wehmeyer, *et al., Self Determination and Positive Adult Outcomes: A Follow-Up Study of Youth with Mental Retardation or Learning Disabilities.* Exceptional Children, 63(2), 245-255 (1997). Ishita Khemka *et al.*, *Evaluation of a Decision-Making Curriculum Designed to Empower Women with Mental Retardation to Resist Abuse*, 110 Am. J. Mental Retardation 193 (2005).
2. Peter Blanck & Jonathan Martinis, '*The Right to Make Choices': The National Resource Center for Supported Decision Making*, 3 Inclusion 24-33 (2015).
3. Margaret Hatch, Samantha Crane, and Jonathan Martinis, *Unjustified Isolation is Discrimination: The Olmstead Case against Overbroad and Undue Organizational and Public Guardianship*. Inclusion, *3*(2), 65-74. (2015)
4. Jennifer Wright, *Guardianship for Your own Good: Improving the Well-Being of Respondents and Wards in the USA*. International Journal of Law and Psychiatry, 33(5), 350-368 (2010).
5. Pamela Teaster, *et al.*, *Wards of the State: A National Study of Public Guardianship*. Stetson Law Review, 37, 193-241 (2007).
6. H.R. Rep. No. 100-641, at 1 (1987).
7. See, *e.g.,* Valerie Bradley, *et al., What do NCI Data Reveal about the Guardianship Status of People with IDD?.* (2019). Available at: https://www.nationalcoreindicators.org/upload/core-indicators/NCI_GuardianshipBrief_April2019_Final.pdf
8. See, Winsor C. Schmidt, *Guardianship: Court of Last Resort for the Elderly and Disabled*. Durham, NC: Carolina Academic Press (1995); Sandra L. Reynolds, *Guardianship Primavera: A First Look at Factors Associated with Having a Legal Guardian Using a Nationally Representative Sample of Community-Dwelling Adults*. 6 Aging and Ment. Health, 109-120 (2002); Brenda K. Uekert, Richard Van Duizend, R., *Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform*. In Future Trends in State Courts 2011: Special Focus on Access to Justice (2011).
9. National Council on Disability. *New Federal Research Examines Guardianships of People with Intellectual and Developmental Disabilities, finds School to Guardianship Pipeline.* (2019) Available at: https://ncd.gov/newsroom/2019/new-federal-research-examines-guardianships
10. *e.g.,* Jonathan Martinis & Peter Blanck, *Supported Decision-Making: From Justice for Jenny to Justice for All. A Theory to Practice Guide.* Virginia: Something Else Solutions Press. (2019).
11. Jonathan Martinis & Lucy Beadnell. (2021). "*I Learned that I have a Voice in my Future:" Summary, Findings, and Recommendations from the Virginia Supported Decision-Making Pilot Project.* Available at: http://www.supporteddecisionmaking.org/node/488
12. National Guardianship Association, *Position Statement on Guardianship, Surrogate Decision-Making, and Supported Decision-Making*, available at: http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf
13. Lucy Beadnell & Jonathan Martinis, *Re-thinking Guardianship and Substitute Decision-Making: Supported Decision-Making and the Reform of Virginia Law, Policy, and Practice to Protect Rights and Ensure Choice.* Developments in Mental Health Law 39(1), 1-13 (2020).

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