



Missouri Developmental Disabilities Council
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Self-Determination and Guardianship

The Missouri Developmental Disabilities Council's Position:

Because everyone has the right to direct their own lives to the maximum of their ability, 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 the ward's rights to the minimum extent possible.

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 necessary³ – 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 a recent study found that people with disabilities who did not have guardians were more likely to be employed, live independently, have friends, and practice the religion of their choice than those with guardians,⁷ the number of people under guardianship has tripled since 1995.⁸

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 need and want to manage their own lives. For example, when people use Supported Decision-Making, they work with trusted friends, family members, and professionals to help them understand the situations and choices they face, so they can make their own decisions without the need for a guardian.⁹ The National Guardianship Association – an organization made up by and for guardians – has stated that such alternatives should be attempted before ordering guardianship.¹⁰

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 direct their own 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.
- Legislation, such as the recently introduced HB626,¹¹ should ensure that alternatives to guardianship are fully considered before people are ordered or kept under guardianship.
- Legislation and/or best practice should ensure that guardianship proceedings are consistent throughout Missouri, protect the rights of people facing guardianship petitions - including their right to be represented by an independent attorney - and provide that guardianships, when absolutely necessary, only restrict rights to the minimum extent possible.
- Missouri should consult with other states, including Texas and Delaware, that have enacted legislation stressing the importance of self-determination and the use of 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); Laurie Powers *et al.*, *My Life: Effects of a Longitudinal, Randomized Study of Self-Determination Enhancement on the Transition Outcomes of Youth in Foster Care and Special Education*, 34 Child. & Youth Services Rev. 2179 (2012); Janette McDougall *et al.*, *The Importance of Self-Determination to Perceived Quality of Life for Youth and Young Adults with Chronic Conditions and Disabilities*, 31 Remedial & Special Educ. 252 (2010); 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. Jonathan Martinis, *'The Right to Make Choices': How Vocational Rehabilitation Can Help Young Adults With Disabilities Increase Self-Determination and Avoid Guardianship*, 42 J. Voc. Rehab., 221, 222 (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. Human Services Research Institute and The National Association of State Directors of Developmental Disabilities Services, *National Core Indicators Study*. Available at: www.nationalcoreindicators.org (statistics on guardianship provided by representative of HSRI).
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). Available at: http://www.guardianshipcert.org/files/publicpolicy/Uekert_Van_Duizend_Adult_Guardianships.pdf (last visited January 22, 2017).
9. Blanck & Martinis, *supra* note 2.
10. 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 (last visited March 12, 2017).
11. Missouri HB626 (2017), available at: <http://house.mo.gov/Bill.aspx?bill=HB626&year=2017&code=R> (last visited March 12, 2017).

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