



Newsletters of Spectrum Institute are published quarterly. The next newsletter will be released in January 2024.



## National Spotlight on Medical Rights

*Federal Rule \* State Appeal \* Guidebooks*

Patients, Families, Providers, and State Officials Are Being Educated About the Medical Rights of Adults with Mental or Developmental Disabilities

One of the biggest pipelines to guardianship is from the medical community. Health care providers for patients with mental or developmental disabilities often tell family members that their loved one needs a guardianship or conservatorship because they lack the "capacity" to make their own medical decisions.

All too often, this advice is based on a diagnosis of dementia or a developmental disability -- and the assumptions that go along with such a diagnosis -- rather than being grounded in a thorough evaluation of the patient's functional abilities with or without reasonable accommodations. Generally, medical personnel recommending guardianship have not evaluated the possibility of medical supported decision-making (SDM). When a

guardianship petition is filed, most judges grant the petition without exploring less restrictive options such as SDM, powers of attorney, or designation of a medical surrogate for the patient.

The medical pipeline to guardianship, based on a failure to perform proper assessments or an exploration of viable alternatives, is a form of disability discrimination. A proposed federal rule from the Department of Health and Human Services, once final, will clearly notify medical providers of their duty not to discriminate -- a duty that may require them to seriously consider SDM. An appeals court in New Jersey is being asked to instruct judges and lawyers on this issue. New guidebooks released by the Alternatives to Guardianship Project in Missouri inform patients of their rights, tell parents how to be effective advocates, and advise health care providers of their legal duties to respect the medical rights of adult patients with mental or developmental disabilities.

Spectrum Institute is involved in all of these endeavors. We published a report for medical providers about the federal rule, we were joined by nine other organizations on a legal brief we filed in the New Jersey appeal, and we produced the guidebooks for the Alternatives to Guardianship Project. We are also working with the American Academy of Developmental Medicine and Dentistry (AADMD) to advance the medical rights of this patient population.

We need your help so that we can continue our education and advocacy efforts to promote the medical rights of these patients and, in doing so, to reduce the number of unwanted and unnecessary guardianships. Please [make a donation](#) to support this important work.



Thomas F. Coleman  
Executive Director

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## AADMD Magazine Has Cover Story on Medical Decision-Making Rights

*Helen: The Journal of Human Exceptionality* is the official magazine of the American Academy of Developmental Medicine and Dentistry (AADMD). Helen is a launch pad for inclusive health. Persons with different abilities, family members and clinicians all take center stage.

The September 2023 issue of Helen includes an article written by Thomas F. Coleman, executive director of [Spectrum Institute](#) and legal consultant to the [Alternatives to Guardianship Project](#). Titled "Medical Decision-Making Rights: What You Should Know," the article offers advice for patients, parents, and providers.

- Patients are encouraged to know their rights, to be involved in medical decisions, and to consider having a supported decision-making arrangement.
- Parents are advised to develop a transition plan for teens as they become adults, to respect the rights of their adult son or daughter, and to be an advocate to protect those rights from being violated.
- Health care providers are told to obey the law, to offer disability accommodations to patients with developmental disabilities, and to educate medical staff about alternatives to guardianship if there are concerns about a patient's capacity.

The article also advises professional organizations, such as AADMD and state medical, dental, nursing, hospital, psychological, psychiatric, and social work associations to convene workgroups on the decision-making rights of adult patients with developmental disabilities. They should identify or develop training materials and webinars on this topic. Annual meetings and professional conferences should include sessions to assist members acquire the skills necessary to respect the rights of these patients.

To read or download the full article, [click here](#).



## Proposed Rule on Disability Discrimination by Federally Funded Health Care Providers

Spectrum Institute has produced a new report for the Alternatives to Guardianship Project. The report comments on a proposed rule by the federal Health and Human Services Department (HHS) clarifying prohibitions on disability discrimination by hospitals, doctors, dentists, and other health care providers who receive federal funds. The rule affirms the rights of adult patients with mental or developmental disabilities and specifies the duties of providers with respect to this patient population. The report will help providers comply with federal law. It also offers guidance to patients and their families and other supporters who may want to file complaints with HHS for any noncompliance. For a copy of the report, [click here](#).



## Appeals Court Accepts Legal Brief from Spectrum Institute

The Appellate Division of the New Jersey Superior Court entered an [order](#) on September 8, 2023, accepting a friend-of-the-court brief filed by Spectrum Institute.

The brief urges the court to issue an opinion that not only protects the medical rights of Peter Brumlik, a young college student on the autism spectrum, but gives guidance to judges and attorneys in other guardianship cases involving adults with developmental disabilities

Also on the brief are Easterseals New Jersey, The Arc of New Jersey, American Academy of Developmental Medicine and Dentistry, Quality Trust for Individuals with Disabilities, Inc., Mental Health Advocacy Services, New Jersey State Office of the Public Defender, Autistic Self Advocacy Network, Center for Estate Administration Reform, and the Alternatives to Guardianship Project.

New Jersey attorney Nina Weiss is local counsel on the brief. Kelly McGuire, staff attorney with Disability Rights New Jersey, represents Peter on appeal. The ACLU of New Jersey will file a brief in the appeal later this month.

For information about the participating organizations, [click here](#). To read or download the brief of Spectrum Institute, [click here](#). *(Photo: Peter Brumlik)*



Guidebook for  
Patients,  
Families, and  
Providers  
on Medical  
Decision-  
Making

On behalf of the Alternatives to Guardianship Project, Spectrum Institute has produced a comprehensive guidebook on the medical decision-making rights of adult patients with developmental disabilities. Although some of the information is directly relevant to Missouri patients, families, health care providers, state agencies, and professional associations, much of the guidebook applies to stakeholders in other jurisdictions as well. The publication includes an annotated bibliography of applicable state and federal statutes, regulations and court cases. To access the guidebook, [click here](#).

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Email:

[tomcoleman@spectruminstitute.org](mailto:tomcoleman@spectruminstitute.org)

Website:

<https://spectruminstitute.org/>



Spectrum Institute, 1717 E. Vista Chino A7-384, 92262, Palm Springs, US