



Newsletters of Spectrum Institute are published quarterly. The next newsletter will be released in October 2023.



Signs of Slow But Steady Progress

Momentum for Guardianship Reform Builds

For years, it seemed as though no one cared about dysfunctional state guardianship and conservatorship systems.

Within these systems, attorneys failed to defend clients, jury trials were nonexistent, and appeals were rare. The media paid little attention.

But with persistent advocacy of a small core of activists throughout the nation, and stimulation from celebrity victims such as Britney Spears, things began to change. Slowly.

Media started paying attention. Webinars began happening. Politicians showed a bit of interest. A few study commissions were launched by judicial officials.

The first state law on supported decision-making as an alternative to guardianship was passed in Texas in 2015. Today, nearly half the states have such laws on the books.

The articles in this newsletter are a testament to the power of perseverance. Congressional action to reign in systemic guardianship abuse may soon occur. Violations of rights are being appealed. Existing cases are being dismissed. Investigative reporters and book authors are educating the public. Alternatives to guardianship are starting to be seriously explored.

Spectrum Institute has been a leader in the movement for guardianship and conservatorship reform. Much of our work is done through volunteerism. However, we need financial help to pay for basic operating expenses. Please [make a donation](#) to support our important work.



Thomas F. Coleman
Executive Director



"Guardianship Bill of Rights Act" Introduced in the United States Senate

[S 1148](#) is called the *Guardianship Bill of Rights Act*. Introduced by Senator Bob Casey (D-PA) [photo] on March 30, 2023, the bill has been assigned to the Senate Committee on Health, Education, Labor, and Pensions.

Co-sponsored by Senator John Fetterman (D-PA), Senator Elizabeth Warren (D-MA), and Senator Bernie Sanders (D-VT), the bill would "establish rights for people being considered for and in protective arrangements, including guardianships and conservatorships, or other arrangements, to provide decision supports."

The bill directs the Secretary of Health and Human Services to establish a Guardianship and Other Protective Arrangements and Supported Decisionmaking Council. The Council would advise the Secretary and the

Attorney General on standards for the inherent civil rights of a covered individual in a guardianship, a conservatorship, or another protective arrangement, including standards related to: due process, voting, marriage, finances, health care, residence, visitation and association, religion, travel, communication, and other areas of decision-making and self-determination.

The Secretary, through the Administrator of the Administration for Community Living, with significant input from the Council, would develop standards for establishing, reviewing, modifying, and discontinuing any protective arrangement for a covered individual, including guardianships and conservatorships, including standards for: establishing a protective arrangement; guaranteed representation by an independent, qualified, and compensated lawyer for the covered individual being considered for a protective arrangement or in a protective arrangement; access to due process while the individual is being considered for a protective arrangement and while in a protective arrangement; ordering limited protective arrangements when less restrictive arrangements, such as supported decisionmaking arrangements, are not appropriate; and options for full restoration of rights for a covered individual in a protective arrangement.

The Attorney General and the Assistant Attorney General for Civil Rights, with significant consultation with the Council, would establish reductions in the amount of federal grants that will be made available to a State or Indian Tribe if the State or Indian Tribe violates the standards to protect inherent civil rights.

If this bill were to pass and be properly funded, it would stimulate meaningful guardianship and conservatorship reforms in states throughout the nation. As the saying goes: "Follow the money!" States that fail to adhere to these standards would lose or have existing federal grants reduced.

For more information about the bill, [click here](#). For a list of members of the Senate Committee and contact information for them, [click here](#). Please send them an email to let them know your views on the bill and the need for federal regulation of state guardianship and conservatorship systems.



Guardianship Appeal Promotes Civil Rights in New Jersey

Peter Brumlik Wants Both His Freedom and Systemic Reform

Peter Brunlik is an intelligent and articulate 20-year-old with hopes and dreams for a successful future. Peter, who finished high school with good grades, is now attending college.

Peter, like many young adults his age, is opinionated. He knows what he likes and dislikes and who he wants to spend time with. He is happy living with his father. He fears his mother and says that he has been abused by her. By choice, Peter has not seen his mother in more than two years.

Soon after Peter moved out of his mother's house just before turning 18, she filed a complaint in the superior court, claiming that Peter was fully incapacitated and needed a plenary guardian of the person and estate. Peter denied the allegations and demanded jury trial.

Peter developed a strong defense, executing a supported decision-making (SDM) agreement and powers of attorney (POAs) for health care and finances. He lined up an array of a dozen witnesses to testify at trial – a forensic psychiatrist, his therapist, an accountant, the lawyer who drafted the SDM and POA documents, a teacher, relatives, and other trusted adults – to affirm his capacity to manage his own affairs despite having autism.

Just weeks before trial, Peter's mother withdrew the complaint and sought an unconditional dismissal. Peter agreed. The guardian ad litem (GAL) did not oppose a dismissal.

Unfortunately, the judge decided to postpone a dismissal, placing illegal and unconstitutional restrictions on Peter for the next two years -- despite the lack

of a valid finding of incapacity and without due process of law.

Peter has been ordered to attend therapy on a regular basis and to submit to interrogations by the GAL about all aspects of his life every six months. Over Peter's objection, the GAL has been given access to Peter's confidential therapy records and can send Peter's mother information about the content of these therapy sessions as well as the private details of Peter's life.

Peter has appealed to the Appellate Division of the New Jersey Superior Court. A friend-of-the-court brief (*amicus curiae* brief) -- supporting Peter's appeal and calling for an appellate ruling to stop due process violations by trial courts -- will be filed by Spectrum Institute, Easterseals New Jersey, 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. For a description of these organizations, [click here](#).

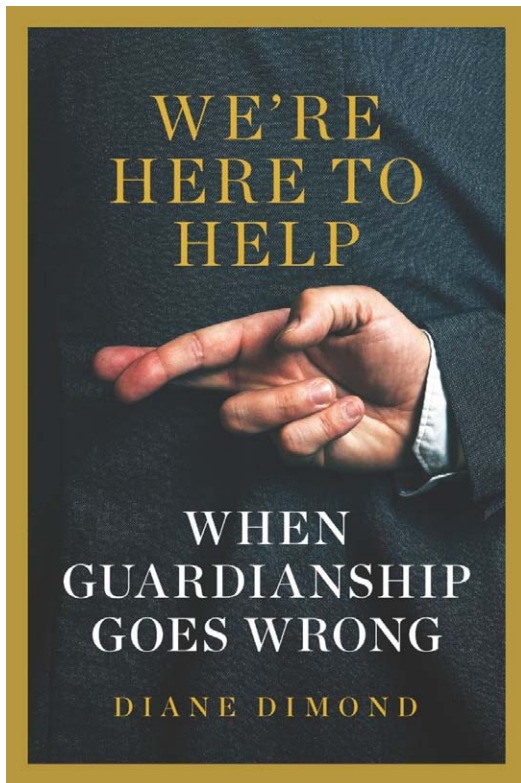
Once Peter is freed from judicial control over his life, he wants to become an advocate for guardianship reform. Peter, who is on summer break from college classes, just returned from a trip to India. His quest for freedom has been supported by his father, Charles Brumlik, since the time the guardianship case was initiated.

Charles sees his son as a model citizen. "Peter is a world traveler, a college student, and a kind empathetic guy. He is a volunteer for political reform, takes care of himself, and is rapidly improving himself. He had zero issues with police, no fights, no addictions, no accidents, no medical issues."

Attorney [David Giles](#) provided Peter with excellent representation in the superior court. Kelly McGuire, a staff attorney with [Disability Rights New Jersey](#) is representing him on appeal. [Thomas F. Coleman](#) wrote the *amicus curiae* brief and [Nina Weiss](#) of Pennington, NJ is serving pro bono as local counsel for the organizations submitting that brief. It will be filed with the Appellate Division in September 2023.

To read or download the motion for stay of conditions pending appeal, [click here](#).

Photos: (from left to right) Peter with his father; Peter; Peter and his friend Eric on a hiking trail in New Jersey.



Book Review

by Thomas F. Coleman

We're Here to Help: ***When Guardianship Goes Wrong***

We're Here to Help is very well written. The book is both easy to read and well documented. The author provides readers with a snapshot of the national landscape by telling stories of celebrities and ordinary citizens alike who have been victimized in state guardianship proceedings.

The recurring message throughout the book is that no one is safe from the grip of guardianship. All it takes is an accident or unexpected illness. Any of us could be targeted by a guardianship petition by anyone at any time.

The book places the responsibility for this mess where it belongs: on the judges who run the state guardianship systems. State courts lack accountability – a necessary ingredient for justice.

The timing of the book's publication is perfect. It coincides with the recent introduction of a bill ([S. 1148](#)) in the United States Senate by Senator Bob Casey, titled "Guardianship Bill of Rights Act." The bill uses a "carrot and stick" approach which would provide incentives for major reforms to state guardianship systems.

When the bill is eventually called for a hearing before the Senate Health, Education, Labor, and Pensions Committee, author Diane Dimond should be called by Committee Chair Sen. Bernie Sanders as the first witness to testify, with *We're Here to Help* introduced into evidence as Exhibit A.

Thomas F. Coleman is the legal director of Spectrum Institute.

Release date is October 13, 2023. To pre-order the book at a discounted price of \$26.60 through **Thriftbooks**, [click here](#).



Human Interest Story Has a Happy Ending

*Ryan Morris is
Reunited with
His Family*

Teri Sforza, a columnist with the Orange County Register, has been writing for years about the quest of Monica Mukai to rescue her nephew Ryan Morris from the nightmare of abusive and neglectful conservatorship proceedings in California. [Story after story](#) were heart wrenching and maddening until finally, on May 14, 2023, the paper ran an article headlined ["After 29 years of forced separation, identical twin comes home."](#)

Ryan and his twin brother Ronald were separated shortly after they were born in January 1994. Because their mother had a history of mental illness and had been neglectful during pregnancy, the state took both infants into custody. Tamara Mazzei Mukai, known to Ryan as "Nona," (the word for grandmother in Italian) was willing to raise both boys but the state only released Ronald to her. Ryan, who was diagnosed with cerebral palsy, was too frail.

Since Ryan was prone to seizures, officials with a child services agency told the grandmother that he needed placement in a specialized foster home. The foster mother eventually cut off all visits from Ryan's biological family. She was later allowed to adopt him.

Over the years, Monica and her mother were able to document a pattern of abuse and neglect by the adoptive mother. But the courts downplayed the severity of the problem. The adoptive mother was appointed as Ryan's conservator when he turned 18. This opened up a series of new court proceedings, including Ryan entering an "arranged" marriage with a much older man who had been his caregiver at the foster home. Ryan thought the ceremony was a baptism. Next, a court appointed the new husband as Ryan's conservator.

Eventually, after persistence and more litigation, the adoptive mother was criminally prosecuted for abuse and the husband was removed as Ryan's conservator. But rather than appointing Monica as a replacement, the court appointed the public guardian. After proving that this agency had neglected Ryan's needs, and demonstrating her own competence, Monica was appointed as her nephew's conservator. This process took an additional year of litigation.

As soon as Monica had the conservatorship order in hand, Ryan moved to Orange County to live with his aunt. He and his Nona are able to visit as often as they wish. Ryan is getting the medical attention he needs, as well as the recreation and social interaction that he had missed for more than two decades.

Monica expressed her gratitude to Thomas F. Coleman, legal director of Spectrum Institute, for the advice and encouragement he provided to her for the past several years. "Ryan is finally under my Conservatorship and safe. I want to THANK YOU kindly for all your dedication and care in helping this become a reality."

Related: Coleman, "Case Tests Limits of Right to Marry," Daily Journal (Feb. 1, 2018) - [Link](#)



California Conservatee Has Her Rights Restored

AB 1663 is Being Implemented

Marie Bergum was [featured](#) last year in the ABC-10 documentary series on conservatorship reform. Titled "The Price of Care," the series by investigative reporter Andy Judson was nominated for a prestigious Peabody Award.

In the television segment, Marie explained that she felt "trapped" after her parents had her conserved at the age of 21. Marie said that, as an adult, she wanted freedom. Instead, she had to get consent to do ordinary things like leaving the house or hanging out with friends.

Eventually, Marie found a self-advocacy group that put her in touch with Suzanne Bennett Francisco, an advocate and disability expert who is well-versed in helping adults develop a supported decision-making arrangement as a way to escape a conservatorship.

The first step in the process of having her rights restored was to get a regional center assessment. "That assessment did recommend she have some of her rights – and if she had certain supports then she could have some of those rights back," Francisco told ABC-10.

Marie's quest to escape conservatorship coincided with the passage of AB 1663, a bill signed into law by Gov. Gavin Newsom on September 30, 2022. The new law provides procedures for someone in a conservatorship to petition for restoration of their rights because they are sufficiently protected by a supported decision-making arrangement.

On June 15, 2023, the American Civil Liberties Union issued a [press release](#) announcing that the conservatorship of Marie Bergum was dismissed. Her wish for freedom was granted by a superior court judge.

Through the press release, Marie explained: "With supported decision-making, I get help from people I trust to make my own choices. I want people to understand that conservatorship is not the only way, and that people with disabilities can make choices and learn and live their own lives."

As an [advisor](#) to the Alternatives to Guardianship Project in Missouri, Marie is lending her experience to help others advocate for guardianship and conservatorship reform.

Related: "My Human Rights Are Being Violated: Fighting a Family Conservatorship," BuzzFeed News (Sept. 20, 2021) - [Link](#)



New Publications for Missouri Project Are Helpful Elsewhere

For the past year, Spectrum Institute has been providing consulting services to the Alternatives to Guardianship Project in Missouri. The project is operated by Hulme Resources, Inc. and receives federal funding through the Missouri Developmental Disabilities Council.

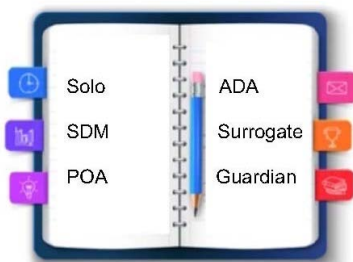
Through its consulting services, Spectrum Institute has been producing educational materials on alternatives to guardianship. The most recent publications focus on medical decision-making options for adults with developmental disabilities.



Transitioning to Adulthood: Resources for Patients, Parents and Medical Providers

This annotated bibliography directs readers to a variety of resources to help patients with developmental disabilities have an effective and meaningful relationship with doctors, clinics, and hospitals.

While some materials are helpful to patients of any adult age, most of them are geared for teens who are preparing to assume primary responsibility for their medical care once they become adults. The bibliography has four sections: For Patients, For Parents, For Providers, and Research. To access this document, [click here](#).



Medical Associations Receive Report on Patient Decision Making Options

The Alternatives to Guardianship Project has sent a report on decision-making options for patients with developmental disabilities to medical associations and disability rights stakeholders in Missouri.

The report explains that such decision making should not be an all (independent) or nothing (guardianship) proposition.

Other options exist for medical professionals to receive informed consent for medical services and medications. Medical and disability stakeholders were invited to work with us in identifying ways to improve the medical decision-making evaluation process and to better protect the rights of this patient population. For a copy of the report, [click here](#).

Please show your support for our work by making a donation. Since we are an IRS-approved 501(c)(3) charitable foundation, donations to Spectrum Institute are tax-deductible as allowed by federal law.

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