



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. We feature evidence-based best practices, advice to navigate the ability lifestyle, tools for advocacy & more. The journal represents the cross-specialties composed of healthcare, education and policy makers along with the disability community (families, self-advocates and caregivers). We're proud to have contributors made up of all the movers and shakers within the community of people with disabilities, along with their families, caregivers and advocates. (Description from the magazine's website.)



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Medical Decision-Making Rights: What You Should Know

Sep 10

by Thomas F. Coleman



Parents have the right to make medical decisions for their children. But when a teenager turns 18, this parental authority comes to an end. With adulthood, a person gains the right of medical self determination, regardless of their disability status. That right can only be taken away by a court order.

Medical decisions can be simple or complicated. Simple decisions include the date and time of a doctor's appointment, who the primary doctor will be, whether someone attends the appointment with the patient, having a routine exam, having blood drawn or an x-ray taken, getting a flu shot, having a dental exam or teeth cleaning, or having an eye exam, or getting glasses to improve the patient's vision. Only simple consent is needed for these procedures and almost anyone can give simple consent.

It's common for both health care providers and parents to become anxious when a child with developmental disabilities transitions to adulthood. Questions about capacity may arise. Does the patient have the ability to understand complicated medical procedures? Can the patient give informed consent? Should the medical provider allow the parents to participate in medical decision-making? Can the provider release medical records to the parents without the patient's consent? Can the patient even give such consent?

Medical providers must comply with federal and state statutes and regulations governing health care services and medical confidentiality. Ethical standards require them to get informed consent for complex or risky medical procedures—from the patient or a duly authorized representative.

But does an adult patient with a developmental disability have the legal authority to designate a representative? Does such a patient have the authority to sign a health care proxy or a medical power of attorney? Does a provider have a legal duty to recognize and give effect to such documents when they are presented?

Medical providers have a legal obligation not to discriminate against patients on the basis of a physical or mental disability.

Medical providers have a legal obligation not to discriminate against patients on the basis of a physical or mental disability. Refusing an adult patient to make his or her own decisions, with the assistance of chosen and trusted supporters, may violate a provider's duties under the Americans with Disabilities Act (ADA) and similar state laws.



Pres. George H.W. Bush signing the Americans with Disabilities Act (ADA), on the South Lawn of the White House, July 26, 1990.

Sometimes medical providers suggest that parents initiate a guardianship proceeding as an easy way to avoid legal and ethical questions. If a parent becomes a guardian, then the parent can continue to make medical decisions even though their child has become an adult. But even though a guardianship may make things easier for a health care provider, it has consequences for the patient. A guardianship takes away the right to make medical decisions, to control access to medical records, and to delegate medical decision-making authority to a trusted person.

This article provides information to adult patients with developmental disabilities on how to assert their medical rights, to parents on how to assist their adult child in doing so without the need for a guardianship, and to providers on how to adhere to ethical requirements, informed-consent laws, and medical confidentiality regulations, while at the same time respecting the right of patients to medical self determination to the greatest extent feasible.

Advice for Patients

Know your rights. Be involved. Consider having a supporter.

Patients should know that when they turn 18, they have the right to make their own medical decisions unless a court order takes that right away from them.

In all but three states (Alabama:19, Mississippi: 21, and Nebraska: 19), the age of majority is 18. This is when a person is considered an adult. And there is no exception for persons with developmental disabilities.

For example, Maryland law states: "... a person eighteen years of age or more is an adult for all purposes whatsoever and has the same legal capacity, rights, powers, privileges, duties, liabilities, and responsibilities ... and the 'age of majority' is hereby declared to be eighteen years." A statute in New Jersey specifically mentions that the age of majority gives an individual the right to consent to medical treatment.

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Some states have laws affirming that individuals with developmental disabilities have the same rights as everyone else. The "Lanterman Act" in California declares: "Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws and the Constitution and laws of the State of California." The United States Supreme Court has ruled that adults have a constitutional right of medical self-determination. A New Jersey statute emphasizes: "Adults with disabilities should be afforded the opportunity to make decisions for themselves, live in typical homes and communities and exercise their full rights as citizens."

Patients also need to know that once they turn 18, they are presumed to have legal capacity to make their own decisions. Anyone who challenges their capacity to make a particular decision has the burden of providing clear and convincing evidence that they lack capacity in that area.

Federal law protects patients from discrimination by a health care provider because of their mental or physical disability. Many states have similar nondiscrimination laws. Discrimination

occurs when a doctor, dentist, or other health care provider claims that a patient lacks

capacity to make his or her own medical decisions, even with assistance, based on a mere diagnosis, assumptions, or biases.

A finding of incapacity must be based on a thorough and professional evaluation of functional abilities and show that the patient does not understand a specific procedure, can't evaluate its risks and benefits, can't communicate a decision, or that the decision is not voluntary.

If a patient is told they lack capacity for a specific procedure, the patient can request a second opinion from a professional who is qualified to make such an assessment. They can appeal the decision to a supervisor. A patient can also request that the provider allow them to have the assistance of a trusted support person to help them make a medical decision as an accommodation under the ADA.

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Patients should be informed that one way to avoid a guardianship may be for them to select a health care representative to have access to their records and to sign what is called a "proxy" which is a document giving a trusted person the authority to make medical decisions for them in situations when a health care provider finds the patient lacks capacity. Most patients would have legal capacity to sign these simple documents, providing the patient understands they are giving someone else the power to make medical decisions for them and that they are voluntarily doing this.

If a patient believes that a health care provider has discriminated against them by refusing to accept their medical decisions or rejecting their designation of a representative or proxy, the patient can file a complaint with an appropriate federal or state civil rights agency with authority to investigate cases of disability discrimination.

If a patient needs help in filing such a complaint, the patient can contact a protection and advocacy organization in their state. Although the name of the organization may vary, each state has one. In California it's called "Disability Rights California." In Missouri it's "Missouri

Protection and Advocacy.” National Disability Rights Network has a [directory](#) of such organizations in each state.

Advice for Parents

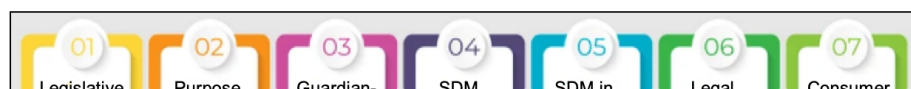
Develop a transition plan. Respect your child's rights. Be an advocate.

Parents who have a child with a developmental disability should begin planning for a transition to adulthood long before their son or daughter turns 18. With proper education and counseling, teenagers with developmental disabilities may have or get the capacity to make their own medical decision—either independently or with help from a person of their choice.

Transition planning should involve a process of educating the patient’s primary care physician, dentist, and any specialists who have been providing care to them as a minor. However, before approaching these professionals with information on the rights of adult patients with developmental disabilities, alternatives to guardianship such as medical directives, designated patient representatives, or health care proxies, parents should first educate themselves on these issues.

Parents should be aware of the basics of patient rights.

Their adult child is presumed to be competent to make his or her own medical decisions. Their child has a right under the ADA to have a support person help them make medical decisions. And federal law allows them to designate a parent as a patient representative who has access to medical records. Very little capacity is needed to designate a parent as a health care proxy. Many states recognize the validity of supported decision-making agreements (SDM) where a trusted supporter helps the patient make medical decisions. Providers have an obligation to show clear evidence of incapacity if they refuse to accept the patient’s authority to make his or her medical decisions or to delegate such authority. Parents have the right to assist their adult child in asking for a second opinion if a provider decides the patient lacks capacity for a particular decision. They have the right to help the patient file an appeal or a complaint for disability discrimination against the provider.



Executive Findings	Purpose & Principles	Guardianship Reform	Consent Agreements	Consent in Schools	Legal Education	Screening Assistance
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Resources like the [Supported Decision-Making Options for Missouri](#) created through the [Alternatives to Guardianship Project](#) are helpful guides to parents navigating the “Turning 18” transition.

Parents should keep in mind that just because a patient may lack capacity for an intrusive and high-risk procedure does not mean they lack capacity to give simple consent for nonintrusive and no risk procedures or informed consent for low-risk treatment. If a high-risk procedure is under discussion, parents should consider having the patient give them the authority to make decisions for that procedure in a document known as a medical proxy. Very little capacity is needed for such a limited delegation of authority. If the parents and provider are in disagreement on the patient’s capacity to sign such a proxy, the parents should ask the state’s disability rights protection and advocacy organization to help them break the stalemate.

If a high-risk procedure is under discussion, parents should consider having the patient give them the authority to make decisions for that procedure in a document known as a medical proxy.

If a provider does accept the patient’s capacity to make medical decisions, independently or with assistance, parents should educate themselves and their child of how to have effective interactions with the provider in the future. Educational resources, including forms, are available to help patients, parents, and providers prepare for scheduled medical appointments. Resources are also available to help with urgent care visits or emergency room interventions.

Advice for Providers

Obey the law. Offer disability accommodations. Educate medical staff.

Some health care providers have considerable experience interacting with patients who have developmental disabilities. For those providers, continuing education classes may be sufficient to keep doctors, nurses, and allied professionals informed of developments on

medical decision-making by patients with special needs. For providers who have little or no experience with this patient population, more extensive training may be necessary.

Administrators and legal staff should become familiar with relevant laws concerning capacity assessments, disability discrimination, reasonable accommodations, and alternatives to guardianship such as medical proxies, health care directives, and supported decision-making.

All providers have a duty to adopt formal policies on patient rights and to obey state and federal statutes and regulations pertaining to informed consent, medical decision-making, patient representatives, health care directives and proxies, and medical confidentiality.

Professional organizations, such as [AADMD](#) and state medical, dental, nursing, hospital, psychological, psychiatric, and social work associations should 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 or professional conferences should include sessions to assist members acquire the skills necessary to respect the rights of these patients.

More resources to learn more about decision-making rights.

- 1. [Guidance for Patients, Families, Providers and Others on Medical Decision-Making](#) (link)**

This comprehensive guidebook on the medical decision-making rights of adult patients with developmental disabilities is now available. It has information for patients, families, health care providers, state agencies, and professional associations. The book includes an annotated bibliography of relevant state and federal statutes, regulations, and court cases.

- 2. [Transitioning to Adulthood: Resources for Patients, Parents and Medical Providers](#) (link)**

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.

3. Medical Decision Making Options: A Summary of Legal and Medical References for Health Care Providers, Patients and Families [\(link\)](#)

This report explains that medical 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 are invited to work together to identify ways to improve the medical decision-making evaluation process and to better protect the rights of these patients.



Photo courtesy of Thomas Coleman.

About the Author

Thomas F. Coleman has been a licensed attorney since 1973. For the past five decades, he has used his legal skills to promote justice and equal rights for populations historically subject to discrimination, including people with developmental disabilities. Coleman has published many policy reports and guidebooks on disability rights and alternatives to guardianship. He offers speaking and consulting [services](#) on these topics. Coleman has been the legal director

of Spectrum Institute since 1987 and is currently a consultant to the [Alternatives to Guardianship Project](#) in Missouri. He recently filed a [legal brief](#) in a New Jersey appeal, urging the court to protect the medical decision-making rights of Peter Brumlik and other adults with developmental disabilities. The American Academy of Developmental Medicine and Dentistry and [10 other organizations](#) joined the brief. Email him at: tomcoleman@spectruminstitute.org



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I'm Courtney Fray - AADMD's Chief Communication Officer - and owner of The Fray Agency, a creative marketing & advertising agency.
