

Adult Patients with Intellectual Disabilities: Issues of Capacity and Waiver under the ADA

by Thomas F. Coleman, J.D.
Legal Director, Spectrum Institute

Supported Decision-Making:

A Critical Analysis



What Public Officials, Professionals, Advocates, and Families Need to Know

Reducing Risks and Limiting Liability

The nondiscrimination policy of Kaiser Permanente specifies that all services must be accessible to individuals with mental or physical disabilities in compliance with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 (Section 504).

Accessibility to services applies to the individuals who have such disabilities, not to their parents, relatives, or associates. The delivery of health care services includes protecting the medical privacy rights of patients as well as obtaining informed consent from them prior to the implementation of medical procedures.

When a patient is a child, a custodial parent or guardian has a right to access medical records or discuss medical information with health care providers. A parent gives informed consent on behalf of a patient who is a child.

However, when a patient becomes an adult at the age of 18, it is the patient whose medical privacy is protected, unless the patient waives the right of privacy and consents to another person having access to the medical records or discussing medical information with a provider. It is the adult patient who must give informed consent, not a parent or other person – unless there is an order issued by a judge or valid delegation of authority executed by the patient.

Legal and ethical issues arise when a doctor or medical staff person is asked to treat an adult patient with intellectual and developmental disabilities – or any patient with a cognitive disability for that matter. Does the patient understand the issue of medical privacy and have the legal capacity to waive such privacy protections? Does the patient have the capacity to render informed consent to medical procedures? If a parent or other person presents a medical power of attorney, allegedly signed by a patient with a cognitive disability, did the patient understand the terms of that document when it was signed? Did the patient have the legal capacity to execute this contract (which is what a power of attorney is)? If a parent or relative of an adult patient presents a document called a “supported decision-making agreement” authorizing that person to participate in the medical decision-making process, does the patient understand the terms in that agreement and did the patient have the legal capacity to enter into such an agreement at the time it was signed?

These are not issues that can be ignored or glossed over lightly. If an adult patient with an intellectual or cognitive disability does not have a conservator with authority to make medical decisions, medical care providers have responsibilities under federal law (HIPAA, Medicaid regulations, ADA, and Section 504) to ensure that the patient has access to these federally-protected rights which are an inherent part of the delivery of medical services. The mere presentation to the provider of a power of attorney or supported decision making agreement does not dispense with the need for a provider to make an independent inquiry and judgment about these difficult issues of capacity and waiver. These issues become even more complicated when the medical services involve questions of possible abuse of the patient by a relative, household member, or person in the immediate circle of support of the patient.

For more information, including a discussion of how medical providers can reduce the risk of violating the ADA and other state and federal laws, and how to limit professional liability, go to: <http://spectruminstitute.org/sdm/>