



Pairing Advance Directives with Supported Decision-Making

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When a young person reaches the age of 18 (19 or 21 in certain states), they are legally considered an adult. For many it's an exciting threshold, full of promise. Still, they may face medical, financial and educational decisions which could benefit from the advice and assistance of others. Unless steps are taken, parents who have routinely participated in IEP (Individualized Education Plan) discussions, doctor's visits or insurance negotiations, could find themselves excluded. Advance directives, tailored to meet the individual's specific circumstances, can be an excellent way to keep trusted relatives involved, while ensuring that young adults direct their own futures.

Unlike guardianship, advance directives do not involve the surrendering of any rights, and they can be dissolved at will. They simply facilitate the *voluntary addition* of others to the individual's *team of decision-makers*. They can be an invaluable aid to supported decision-making, giving "trusted others" access to important records and the right to speak on an individual's behalf.

When considering advance directives, the first step is to assess what the individual can handle independently and under what circumstances they might benefit from additional perspectives and help. Special needs attorneys can then draft documents that are explicit about what an agent can and cannot do. The goal should be to retain as much autonomy as possible for the person in question.

Depending upon its precise stipulations, a **health care advance directive**, sometimes referred to as a "health care proxy," may entitle an agent to speak with an individual's physicians, have access to medical records and even make health care decisions on their behalf. It's vitally important that the agent learn as much as possible about the individual's treatment preferences so that, in the event they are called upon to make choices for them, they can act in accordance with the person's wishes.

A **financial power of attorney** can also be as general or restrictive as desired. Typical forms of authority include bill-paying, advocacy concerning government benefits, and management of bank accounts and investments.

The **education power of attorney** is a relatively recent, and very practical, addition to the advance directive category. Many individuals with developmental disabilities continue to take classes well after the age of 18, eventually attending technical school or even college.

Having a reliable adult assist them in exploring alternatives, negotiating services or dealing with enrollment paperwork can allow them to concentrate on learning. To reduce the possibility of future conflict, it's a good idea to have your special needs attorney send a draft to the local school district for feedback.

Working with an Attorney

With the exception of the education power of attorney, which is not yet covered by most state statutes, there are many standard advance directive forms available online. In general, though, the needs of individuals with disabilities are not well served by them. They are designed for a general audience and meet minimal legal standards across the 50 states. They lack the flexibility needed for the optimal balance between independence and assistance needed by many individuals with intellectual and developmental disabilities.

The lawyer who drafts such documents represents the person with disabilities, not the agent to be designated, and both parties should meet with legal counsel. To ensure that the consultation goes as smoothly as possible, let the attorney know ahead of time if the individual is sensitive to certain stimuli or has a distinct conversational style. If there's an optimal time of day for the appointment, work with staff for the best scheduling. While the attorney will, of course, welcome the input of family members, it's critical that the client's wishes be thoroughly understood, respected and deferred to.

If properly drafted, advance directives can provide just the right mix of assistance and autonomy. If designed with care, they can be instruments of empowerment for individuals with intellectual and developmental disabilities.

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