

Finding a Balance of Autonomy, Support, and Assistance: Using Supported Decision-Making Agreements and Powers of Attorney

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As a growing trend, an individual with a disability can plan for guidance and assistance with a supported decision-making agreement. Along with such an agreement, <u>a financial power of attorney and a healthcare advance directive completes the plan</u>, with an emphasis on personal autonomy.

Let's consider fictional Sasha, who may benefit from this type of coordinated plan. Sasha is 19 years old, has a developmental disability, goes to school full time, and works part time at a pet store. Supported decision making is a concept that allows Sasha to maintain full decision-making authority herself. She can include others to assist in gathering and evaluating information to help her make decisions about healthcare, living arrangements, education, and financial transactions. A handful of states have enacted statutes in which an individual can create a supported decision-making agreement, often with model forms. Even without the framework of state statutes, Sasha can prepare an agreement to designate her supporters. For some types of decisions, Sasha will need to sign additional documents or releases to supplement her agreement.

Sasha's agreement will need to include:

- Names of the individuals—Sasha's name, plus the name of her supporter. Sasha should trust her supporter completely and trust that her supporter is willing and capable to help her. If Sasha wants more than one supporter, she should have separate agreements to cover different topics or different time periods.
- The timeframe for the agreement—It may be for a specific time period, or with no end date, or date specific. Sasha can revoke the agreement any time.

- The types of decisions with which Sasha wants help—For example, she may need help making decisions about educational programs, medical appointments, or financial matters.
- The types of information that her supporter may access—For example, her supporter may need to access Sasha's school information to help her plan her work schedule.
- Additional documents—If a supporter needs to access personal information from an
 educational institution, Sasha will need to sign a release under the Family
 Educational Rights and Privacy Act (FERPA). If Sasha's supporter needs to access
 Sasha's medical information, Sasha will need to sign a Health Insurance Portability
 and Accountability Act (HIPAA) release for her medical provider. Finally, many
 financial institutions will have forms to allow a third party to access information on
 an account, without allowing control of the account.

A supporter can be given broad access to personal information, so Sasha needs to choose a supporter who will use her information for her interests. Although the supporter has significant power, that power is not authority to make decisions for Sasha. Furthermore, designating a supporter is not an indication that Sasha is incompetent to make her own decisions or needs a guardian, but rather Sasha's recognition that she may desire assistance with these decisions.

To complete her plan Sasha will need more than just her chosen supporters. She will need to complete powers of attorney for healthcare and finances. A healthcare power of attorney can protect Sasha if she is incapacitated and cannot make healthcare decisions for herself. Such a document may go by different names in different states—"healthcare proxy," "power of attorney," "advance directive." By completing a healthcare power of attorney, Sasha can choose her healthcare agent instead of state law or a court deciding who will decide for her. Furthermore, a power of attorney will not override her own authority but will be a voice to express Sasha's wishes if she cannot do so herself.

Similarly, a financial power of attorney is a way for Sasha to designate someone to act for her if she cannot manage her finances herself. A financial power of attorney can be broad, dealing with all financial matters in the same way Sasha could herself, or it can be narrow and specific, only allowing management of a bank account or other specific resource. A financial power of attorney gives Sasha flexibility and control. Sasha can choose when the power of attorney becomes effective—whether right away to share responsibility with her agent, or only in the future if she becomes incapacitated (which is called a "springing" power).

Sasha remains in control too, because she keeps all her power to act for herself, and the agent named in her power of attorney must act only according to her wishes. Furthermore, Sasha can revoke the power of attorney at any time to change her agent. Finally, in all cases, the agent must answer to Sasha for any action taken. In legal terms, this means the agent owes Sasha "fiduciary duties" of loyalty, good faith, and accounting.

With a combination of a supported decision-making agreement, healthcare power of attorney, and financial power of attorney, Sasha has a well-balanced plan for help when she wants it, from the supporters of her choice. To get started, Sasha and her supporters may wish to check out one or more of these resources:

- National Resource Center for Supported Decision-Making: supporteddecisionmaking.org
- ACLU Supported Decision-Making Resource Library: aclu.org/other/supporteddecision-making-resource-library
- National advocacy and service organizations, such as The Arc, and their local and state chapters

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