

Guardianship and Alternatives: Frequently Asked Questions

What is guardianship?

Guardianship is the means by which the state (through a court proceeding) takes the right and power to make choices away from a person (often called the "ward") and gives the power to another, the guardian. In New York, the ward loses all legal capacity to make decisions about healthcare, finances, where to live, who to associate with, what kind of education or work s/he will have, and every other aspect of her/his life.

What is the purpose of guardianship?

Historically, guardianship has been seen as a way of protecting vulnerable persons, including persons with intellectual and developmental disabilities (I/DD). Changes in the way that we understand disability today challenge this view. For example, research indicates that promoting self-determination and inclusion in the community is often the best protection. Even if guardianship may have made sense in the past when no one expected persons with I/DD strive for greater independence, today self-determined and inclusive lives are the goal.

The current law in New York allows parents to obtain guardianship, often without even a hearing, based entirely on affirmations by healthcare professionals attesting to their child's I/DD and the conclusion that it would be in the child's best interest to have a guardian appointed. This law has been widely criticized by scholars and practitioners and new versions of the law with more procedural protections are being considered by the legislature.

Why do people seek guardianship for their children?

Parents are often told that they need to obtain guardianship when their child with I/DD turns 18 in order to participate in their child's educational planning or to seek benefits from the Office for Persons with Developmental Disabilities (OPWDD). This misinformation often leads parents to seek guardianship without realizing that guardianship entails the total deprivation of their child's rights and without considering available alternatives.

What are alternatives to guardianship?

There are many alternatives, depending on why people think guardianship may be desirable in the first instance. For example, if the issue is financial, there are alternatives

including representative payeeships for SSI payments, authorized representation for Medicaid benefits, joint or limited bank accounts, credit or bank cards with predetermined limits, and powers of attorney. For healthcare, the persons with I/DD may execute a healthcare proxy. Also, New York's Family Healthcare Decisions Act permits involved family members to make decisions on behalf of persons with I/DD without guardianship.

Is supported decision-making an alternative to guardianship?

Yes. It is based on the understanding that all people make decisions and choices with the help of others, but that persons with I/DD may need more or different kinds of help. Supported decision-making allows persons with I/DD to choose trusted others, often family members, to support them in making *their own decisions*. Supports may include gathering information, helping persons with I/DD evaluate the information and understand the consequences of a decision, communicating decisions to third parties and supporting persons with I/DD in taking responsibility for their decisions.

Often the arrangement will be reduced to writing in a contract called a "supported decision-making agreement." Some institutions, like schools or OPWDD may agree to accept such agreements instead of guardianship as, for example, is the case in Washington, DC. Some states, like Texas and Delaware, now have laws requiring private third parties (like doctors, financial institutions, or landlords) to accept supported decision-making agreements. While New York does not yet have such a law, the Supported Decision-Making New York (SDMNY) project, funded by the NYS Developmental Disabilities Planning Council, hopes to develop evidence that will support such legislation in the future.

What are the benefits of supported decision-making?

A person with I/DD never loses her/his rights, including important rights to contract, to vote, to work, to marry—all of which are critical to her/his human dignity and personhood. Making one's own decisions fosters self-determination and teaches a person to learn from bad choices and to make good choices in a way that will serve and protect her/him when her/his parents are no longer able to do so. Being connected to supporters protects against the kind of exploitation or abuse that can occur when a person is isolated and powerless. Supporting persons with I/DD to make their own decisions is the best way to carry out the purpose of laws like the Americans with Disabilities Act, which requires persons with I/DD to be treated equally as others, and the Individuals with Disabilities Education Act, which requires that persons with I/DD have opportunities to lead self-determined lives.