Supported Decision Making is a Right That Needs to Become a Reality

by Thomas F. Coleman

Supported decision making has become a rallying cry for people with developmental disabilities and those who advocate for their rights. The idea is that all people, including those with intellectual or other disabilities, should make their own decisions.

Substitute decision makers should be the exception, not the rule. Adult guardianships should be a last resort, not a routine procedure.

Sometimes a cognitive or intellectual disability is so severe that substitute decision making is unavoidable. But when a guardianship is necessary it should include provisions that respect the preferences of the person who needs support.

Adult guardianships have been part of our legal system for centuries. The principle of “parens patriae” or paternalistic protection is not new.

Social mores teach us that “it takes a village” to care for and protect members of society who are vulnerable. Adult guardianships are the way for the village to designate someone to make decisions for those who are unable to make their own decisions.

However, our notions about people with intellectual and developmental disabilities have changed over the past few decades, especially in recent years. We now have a better social, and even scientific, understanding that people with cognitive and communication disabilities can make decisions regarding their own lives and their own futures if they have proper support.

The movement for supported decision making is emerging in response to our growing understanding of the capabilities of people with disabilities. This is not to say that the principle of “parens patriae” should be abolished entirely. But that principle must accommodate new scientific information. It must also recognize and incorporate the idea that people with developmental disabilities have constitutional and civil rights.

Federal law, and the laws of many states, specify that people with intellectual and developmental disabilities are entitled to live in the least restrictive environments. Government agencies are supposed to protect their rights and should promote independence.

However, because living up to these mandates and honoring these principles requires money and may involve extra staff time, agencies that implement federal and state programs for people with disabilities often do not fulfill their obligations. They may cut corners and sweep difficult issues under the rug.

Among the corner cutters and under-the-rug sweepers are judges, court-appointed attorneys, and other government officials who operate the adult guardianship systems in all 50 states. California is a perfect example of a guardianship system that values efficiency more than it values self determination and independence for adults with developmental disabilities.

The system promotes efficiency so much that it fails to spend money to train judges, attorneys, investigators and service providers on how to evaluate the capacities of proposed conservatees. Tens of thousands of adults with developmental disabilities have their rights taken away without an evidentiary hearing to determine if supportive decision making has been considered as an alternative, and if it has, why it will not work.

The legal requirement that less restrictive alternatives to conservatorships have been considered and are not feasible is a requirement in theory but not in practice.

Proponents of supportive decision making really do not need new laws to be passed. They need existing legal requirements to be implemented. But to make that feasible, we need sufficient funding to allow judges, attorneys, investigators, and others perform the duties they already have under existing laws. Funding and monitoring are the keys to the kingdom of equal rights.

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For more on SDM go to: http://disabilityandabuse.org/supported-decision-making.htm