

**Beyond Guardianship: Supported Decision-Making by Individuals with Intellectual
Disabilities***
A Short Summary from the 2012 National Roundtable

A one-day conversation was held in New York City in October 2012 to discuss the rights of people with intellectual disabilities to make their own decisions, including the impact of the Convention on the Rights of Persons with Disabilities (CPRD). The goal of the meeting was to explore concrete ways to move from a model of substituted decision-making, like guardianship, to one of supported decision-making, consistent with the human right of legal capacity.

What is Guardianship?

Guardianship of an adult is a legal process in which a court determines that a person is not able to make some or all decisions about health care, living arrangements, property and other personal life decisions; that the person is in need of protection; and that there are no less restrictive options for decision-making than guardianship. (“Less restrictive” options means other ways of making decisions that protect the person’s rights and self-determination better than guardianship.) If these conditions are met, a third party is appointed to make legally binding decisions for the person with a disability. Being placed under guardianship removes fundamental rights from the person. Guardianship is a state law issue, with different systems in each state.

What is Supported Decision-Making?

Supported decision-making is a process in which individuals with an intellectual or developmental disability (I/DD) are assisted in making decisions for themselves. Supported decision-making happens when an individual with I/DD is the decision maker, but is provided support from one or more persons who explain issues to the individual in a manner that he or she can understand. There is no one model of supported decision-making.

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD)

There is a new way of looking at legal capacity as a part of internationally recognized human rights. Article 12 of the CPRD challenges the existing system of substituted decision-making (like guardianship). It pushes us to move toward a new framework of supported decision-making. Article 12 states that all people have legal capacity, and that governments shall take appropriate measures to provide people with disabilities access to the support they may require in exercising their legal capacity. (The full text of Article 12 is attached.)

Article 12 breaks the link between evidence of mental and communicative capacity (understanding, appreciation and ability to communicate) and legal capacity (the right to make one’s choices and have them legally recognized). With appropriate support and accommodations, all people can make choices. By moving the context of disability from a medical or social model to a human rights model, the CRPD views legal capacity in a new way. Everyone has legal capacity, which means the right to both make their own decisions and to act on and have those decisions legally recognized.

Challenges and Opportunities

In addition to the ideas in the CRPD, it's an important time to have this conversation. We now have the first generation of people with intellectual disabilities who have grown up with the Americans with Disabilities Act, living in the community rather than in an institutional setting, and may have graduated from high school and even college.

The Roundtable included conversation about legal and other reforms needed in this country around decision-making, and changes that might lead to the end of guardianship as we know it today. The Roundtable participants brought many backgrounds and experiences to the table. They raised a number of important and difficult questions:

- Should we build a bridge between the existing guardianship laws and full supported decision-making?
- Can we revise current standards for guardianship to stress independent decision-making and the supports needed?
- Should implementation take place somewhere other than the judicial system?
- How would decision-making supporters be appointed?
 - What process would be needed to have them legally recognized?
- Where and how do we find the resources needed to create networks of support and trust for individuals?
- How do we prevent abuse and undue influence without denying legal capacity? Given that abuse occurs in the current system, some participants emphasized that the answer should not allow protectionism to inhibit robust use and recognition of supporters.
- How can we protect the integrity of the decision-making process?
 - Do we need standards and expectations for supporters? Should there be a reporting system?
 - Should supporters be required to keep records?
 - What kind of monitoring would be required?
 - Should monitoring differ for different kinds of decisions?
 - How should disputes between supporters and the person with a disability be resolved?
- How would supported decision-making work for other populations? For example, what differences would we find in applying the idea to older individuals with dementia?

Suggestions from Roundtable participants included:

Education:

- Teach decision-making skills to all students, from kindergarten through transition.
- Educate families about the capacity of people with intellectual disabilities, the need to create a circle of supporters, and about alternatives to guardianship.
- Educate professionals who do capacity assessments that capacity is not binary and the legal capacity is not dependent on a particular level of cognitive ability.

- Train judges about the abilities of people with intellectual disabilities, about the human right of legal capacity, and about alternatives to guardianship.
- Provide professional development in teaching decision-making, self-advocacy, and self-determination skills to people in the special education system.
- Educate health care professionals and financial professionals about non-traditional ways people communicate, about accommodations in general, and about accommodations in offering choices.
- Educate all children about human rights, disability rights and that disability is a natural part of the human condition.
- Teach people how to be supporters and how to provide circles of support.

Advocacy and Mobilization:

- Self-advocates must be leaders in any mobilization.
- Identify existing successful systems of supported decision-making.
- Recognize and include race and class differences.
- Develop pilot projects and tell success stories.
- Develop practical tools for professionals to understand and assist with supported decision-making.
- Understand that change is not going to happen all at once.

Legal Framework:

- Ensure supported decisions are legally recognized by appropriate third parties.
- Create a new legal framework consistent with the right of legal capacity.
- Use changes in Medicaid at the federal level to stress and facilitate supported decision-making.
- Encourage the U.S. Departments of Education and Health and Human Services to inform states that parents of children aging out of special education should not be told to seek guardianship. Self-advocates and their families should be told of alternatives to guardianship.
- Make better use of power of attorney, health proxies and other options at the state level.
- Create forms in simple language for use by self-advocates.
- Incorporate supported decision-making as a necessary alternative that must be tried and failed before guardianship can be imposed.
- Place limitations on some kinds of decisions guardians can make.
- Limit the number of cases professional guardians can take on.
- Reform and ease procedures for people currently under guardianship to end the guardianship and have their rights restored.
- Use the existing criminal system to punish and prevent abuse of people with intellectual disabilities.
- Urge the American Bar Association (ABA) to address issues of legal capacity in its Model Rules of Professional Conduct in light of CRPD.

- Ask the ABA and other leaders in the legal community to support education on human rights beginning in primary school and promote accountability.
- Work with others toward generating recommendations and principles for establishing supported decision-making.
- Connect with international organizations, including Inclusion International and the Open Society, as well as groups in Canada and Europe.
- Share best practices and law reform proposals and strategies.
- Consider creating new laws to develop a system for the appointment of supporters, preferable outside the judicial system and to provide for protection from abuse and exploitation, consistent with CRPD.
- Create independent human rights monitoring of the recognition of legal capacity in courts and financial institutions.

Key Roundtable Themes

In conclusion, some key themes emerged from the Roundtable:

- ❖ The importance of sharing success stories.
- ❖ The need to develop standards and guiding principles that can be adopted by other organizations.
- ❖ The need to compile existing information in one place, and track new information and efforts as they emerge in the U.S.
- ❖ The need for additional research, including how supported decision-making is working in the U.S. It will be important to evaluate any pilot programs to see what effect they are having.
- ❖ The need to clarify the role of self-advocates families, educators, and transition professionals.
- ❖ The need to develop a clear plan for next steps, including short term and long term solutions for the future.
- ❖ The need to identify barriers to guardianship reform.
- ❖ The need to develop alternatives for people currently under guardianship as well as options for people without guardianship now.

*The invited Roundtable participants included experts and stakeholders from a variety of disciplines and organizations, including: lawyers; physicians; educators; service providers; siblings; parents; self advocates; representatives from national and state policy, civil liberties, and advocacy organizations and guardianship associations; members of the judiciary; and participants from several government agencies. The Roundtable was convened by two Commissions of the American Bar Association (ABA), the Commission on Disability Rights and the Commission on Law and Aging, with support from the Administration on Intellectual and Developmental Disabilities (AIDD) in the U.S. Department of Health and Human Services, and was made possible with additional funds from the New York Community Trust and the New York State Commission on Quality Care.

For more information and materials on the Roundtable, please see <http://www.americanbar.org/groups/disabilityrights/resources/crpd/article12.html>.