
Supported Decision-Making's Impact

- Supported decision-making spurs conversations about the wants and needs of individuals with intellectual and developmental disabilities, their choices, and the ramifications of those choices.
- People in their 20s and 30s who have relied on parents to represent them are expanding their support circles to include contemporaries to voice their preferences for employment and lifestyle changes.
- Parents are planning for the future by bringing to the table the next generation of supporters – often the individual's siblings who know her values and how she expresses herself.
- Older individuals, especially those scarred by institutionalization, are making sure their network supporters respect their preferences as they face changing health needs.
- Community leaders, employers, school administrators, judges, doctors, merchants and residents are learning about the capacity of individuals with disabilities and the right to self-determination.
- Individuals with disabilities are gaining both a voice and a presence in the community.



THE CPR-NONOTUCK SUPPORTED DECISION-MAKING PROJECT

www.supporteddecisions.org



Center for Public Representation
22 Green Street
Northampton, MA 01060
413-586-6024
www.centerforpublicrep.org



Nonotuck Resource Associates, Inc.
425 Prospect Street
Northampton, MA 01060
413-586-5256
www.nonotuck.com

SUPPORTED DECISION-MAKING: A promising alternative to guardianship

What is supported decision-making?

Supported decision-making is an alternative to guardianship that allows an individual with a disability to work with a team and make choices about his or her own life. Under this model, the individual designates a support network, sometimes called a circle of support, to help make decisions.

Supported decision-making maximizes independence and promotes self-advocacy. It replaces substituted decision-making by a guardian with supported decision-making by the individual, assisted by a family and/or community support network.

We all engage in supported decision-making on a daily basis. We confer with family members, friends and consultants before we decide to change jobs, go out on a date, buy a used car or undergo a medical procedure. In the same way, individuals with disabilities can discuss pending issues with network supporters who help them reach their own decisions.



Who is on an individual's network, team or circle of support?

An individual's network may include family members, caregivers, providers, friends, mentors and other community members. A supporter may be designated for a particular area, such as health care or finances, or for all areas. Network supporters, who are chosen by the individual, are people who know the person's preferences, values and goals, and respect his or her autonomy. There is a relationship of trust between the individual making the decision and the network supporters.

Many people with disabilities need assistance making decisions about accommodations, health care, lifestyles and financial matters, but they do not necessarily need a guardian to make those decisions on their behalf.

What is the role of an individual's network or circle of support?

The supporters assist the person so he or she can reach his or her own decisions. They help the person understand the choices at hand, and review options – the pros and the cons – of the pending issue. The supporters also assist the person in communicating his or her intention to others.

THE CPR-NONOTUCK SUPPORTED DECISION-MAKING PILOT PROJECT

The Center for Public Representation (CPR) is a nonprofit public interest law firm dedicated to improving the quality of lives of individuals with disabilities. Nonotuck Resource Associates, Inc., is an established social service provider offering innovative long-term and residential services.



The Pilot Participants: About a dozen Nonotuck clients are included in a pilot project promoting supported decision-making instead of guardianship. Their ages range from the low 20s to the late 70s. They all live in Western Massachusetts, mostly in shared living arrangements with people with whom they have created a home. Some are employed, some are relegated to work enclaves, and some attend day programs.

The Support Networks: Each pilot participant has designated people to be in his or her network of supporters to help make decisions about life matters – friendships, travel, health care, housing, etc. Their networks include brothers, sisters, parents, past and present caregivers, nieces, nephews and friends. The pilot participants are identifying areas in which they need decision-making support and designating the people to provide that support. For example, they might turn to a sibling to talk about whether to get a flu shot or follow through on recommended cataract surgery, and call upon a long-time respite provider to discuss next year's vacation.

CPR and Nonotuck staff are facilitating agreements between the pilot participants and their designated network supporters that identify areas of support and specify supporters' roles. If warranted, CPR will represent participants in probate court.

The Advisory Council: The CPR-Nonotuck Project is backed by its own support network – an Advisory Council made up of individuals with disabilities, parents or siblings of persons with disabilities, judges, doctors, providers, attorneys and nurses. Some have family members with disabilities, and some currently serve as guardians to individuals with disabilities. The Council will offer advice and guidance throughout the process.

Research & Analysis: The Project will keep data on the specific areas (health care, friendships, housing, travel, etc.) pilot participants seek support for decision-making, and on the people they nominate for their support network (family, friends, community volunteers, etc.). The Project will monitor the effectiveness of the relationships to determine if this approach is positive for the participants. Through questionnaires and discussions, the Project will identify its successes and challenges.

In addition, the Project has contracted with the nonprofit Human Services Research Institute (HSRI) to build the evidence base for the construct of supported decision-making. Through a case study analysis, including questionnaires, interviews and onsite reviews, HSRI will identify best practices to determine how this pilot can be replicated as a national or international model of an alternative to restrictive guardianships.