

Supported Decision Making for People with Intellectual and Developmental Disabilities: An Alternative to Guardianship



Outline

- Definition of Supported Decision Making (SDM)
- Commonly Used Types of SDM
- How SDM differs from Guardianship
- SDM Initiatives:
 - United Nations
 - U.S. Administration on Community Living
- What we can all do
- Resources

How do you
make big
decisions?

QC members
take a minute to
share their
decision making
steps or process.



SDM Bottom Line

Supported Decision Making is a right not only to make decisions (with support if needed) but to have those decisions recognized and honored.

SDM recognizes the use of non-speech communication.



Supported Decision Making (SDM)

Definition

SDM is relationships, arrangements, and agreements that assist a person with a disability to make and communicate important decisions.

People with disabilities may choose one or more trusted support persons to assist them including:

- peer support
- community support networks
- natural supports (family, friends) or
- representatives (using a representation agreement).

Source: Robert D. Dinerstein, Developmental Disabilities Lecture Series
The Boggs Center on Developmental Disabilities, April 4, 2014

SDM is Characterized by:

- Accessible and available to all. Lack of resources cannot be a barrier to SDM.
- Support based on the will and preferences of the person (and not on presumed best interests).
- Legal recognition of the support person(s) chosen by the person. Person has right to terminate or change supporter. Others can verify and object if supporters are not following person's preferences.
- Formal support - Registered supporters available for important decisions of legal relevance.
- Informal support - for more everyday decisions.

Common Types of SDM

- Informal conversations for advice with friends, family members, peer support, self-advocates
- Advance directives for health care, “living wills”
- Durable power of attorney
- Health care power of attorney
- Interpreting close personal contact between two people with ID/DD to mean they wish to be intimate (even when non-verbal)

SDM Compared to Guardianship

Guardianship

- Decision making rights are removed from person and given to another person
- Guardians make decisions *for* a person with ID/DD -- even if the guardian consults with the person.
- Guardianship is rarely removed or reduced
- Decisions in best interest standard (evolving now to person's preferences)

Supported Decision Making

- Person keeps all decision making rights
- Person makes decisions *with* help from those they select (even when extensive support to communicate and express decisions is necessary).
- Allows change as person's preferences/needs change.
- Personal preferences more important than best interest.

Problems with Guardianship

- Loss of rights is a high price for guardianship intervention.
- Guardians sometimes over-step areas of decision-making authority awarded by court. Voting, participation in commerce, ability to form personal relationships, etc., all can be hindered.
- Not all guardians consult sufficiently with the person.
- Even when guardians do consult, may not make decision the individual would make if they had legal right to decide.
- Neglect, abuse, financial exploitation and conflicts of interest are still present under guardianship. And may be under SDM.

SDM Initiatives

SDM has been adopted in these countries:

- Canada (British Columbia & other provinces)
- Australia
- Sweden
- Parts of Germany
- Norway
- Czech Republic
- Bulgaria

Source: Robert D. Dinerstein, Developmental Disabilities Lecture Series
The Boggs Center on Developmental Disabilities, April 4, 2014

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

- Based on the U.S. Americans With Disabilities Act
- Frames concerns of people with disabilities in terms of human rights.
- International agreement signed by 149 countries
- CRPD has 50 Articles. Purpose, **Article 1**, is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Source: Robert D. Dinerstein, Developmental Disabilities Lecture Series
The Boggs Center on Developmental Disabilities, April 4, 2014

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

- Article 12, Equal Recognition Before the Law - Supported decision making was introduced as the legal mechanism through which governments could provide people with disabilities support to be able to exercise their legal capacity
- Article 5, Equality and Non-discrimination - Governments should take steps to reasonably accommodate people with disabilities, to promote equality, and eliminate discrimination.

Source: Robert D. Dinerstein, Developmental Disabilities Lecture Series
The Boggs Center on Developmental Disabilities, April 4, 2014

Status of CRPD in the USA

- Signed by President Obama (2009)
- Submitted by Administration to US Senate for ratification (2/3 vote required)(Summer 2012)
- Passed US Senate Committee on Foreign Relations (id.)
- Defeated in US Senate (Dec. 2012)
- Re-submitted to US Senate Committee on Foreign Relations; two hearings held (Nov. 2013)
- Defeated in US Senate (August 2014)
- **Next steps in U.S. – continue to advocate for ratification**
- <https://www.youtube.com/watch?v=pIPAelbZZWY&feature=youtu.be>

Jenny Hatch

Adult with ID/DD in U.S. who opposed guardianship and won right to make decisions using SDM.



Jenny Hatch Justice Project website:
<http://jennyhatchproject.info/>

U.S. Administration for Community Living

Funded a 5 year SDM initiative for Aging and ID/DD and created the National Resource Center on Supported Decision Making to:

1. Compile and publicize SDM success stories
2. Research how SDM is working here and abroad
3. Develop toolkits to assist individuals and supporters to participate in SDM
4. SDM demonstration projects around the country
5. Create an online SDM clearinghouse
6. Provide SDM training and technical assistance

National Guardianship Association

- 2013 revised policies and practices from best interest standard to supporting and prioritizing a person's preferences.
- Encourage and support a person to understand facts and direct a decision, maximize participation of person in making decisions, determine if person has previously expressed preferences
- Identify and advocate for the person's goals, needs, and preferences. Goals are what are important to the person under guardianship; preferences are specific expressions of choice.
- Guardian shall attempt to maximize the self-reliance and independence of the person.
- Guardian shall affirm right to consensual sexual expression.

When is Guardianship typically imposed?

- Youth receiving services move into adult services
- Adults entering service system from wait list
- Important medical care decisions need to be made
- Parents are aging and concerned about future
- Person is not compliant with psychiatric or court-ordered care/supervision
- Abuse, neglect or exploitation of an elder is substantiated
- Other times?

What we can all do....

- Recognize and respect that everyone has an equal right to make their own decisions, regardless of their diagnosis or functional challenges.
- Be respectful of opinions and beliefs that led others to choose guardianship (it was best practice for several decades)
- Assist people of all capacities to express their preferences
- Report abuse, neglect, financial exploitation
- Ask everyone to think about alternatives when guardianship is suggested

Resources & Contact Information

- Robert D. Dinerstein, Professor of Law and Associate Dean for Experiential Education, American University, Washington College of Law, Developmental Disabilities Lecture Series, The Boggs Center on Developmental Disabilities, April 2014, *Implementing Legal Capacity Under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The Difficult Road From Guardianship to Supported Decision-Making*.
- Supported Decision Making: An Agenda for Action, Cathy Ficker-Terrill & Tina Campanella, January 2014, http://www.thecouncil.org/uploadedFiles/Supported%20Decision%20Making_FINAL.pdf
- National Guardianship Association, Standards of Practice 2013 revision: http://www.guardianship.org/documents/Standards_of_Practice.pdf
- National Resource Center for Supported Decision Making: <http://supporteddecisionmaking.org/>
- United Nations Convention on the Rights of Persons with Disabilities webpage: <http://www.un.org/disabilities/default.asp?id=150>

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