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

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

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- Developmental Disabilities Lecture Series
- The Boggs Center on Developmental Disabilities
- April 4, 2014

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<td>• Supported decision-making can be defined as a series of relationships, practices, arrangements, and agreements, of more or less formality and intensity, designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life. . . . [S]upported decision-making [relies] on peer support (for example, ex-users of psychiatric services for people with psychosocial disabilities), community support networks and personal assistance, so-called natural supports(family, friends), or representatives (pursuant to a representation agreement) to speak with, rather than for, the individual with a disability.” (Dinerstein 2011-12)</td>
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<td>• ’Support’ is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. For example, persons with disabilities may choose one or more trusted support persons to assist them in exercising their legal capacity for certain types of decisions, or may call on other forms of support, such as peer support, advocacy (including self-advocacy support), or assistance with communication. . . . (Support can also constitute the development and recognition of diverse, non-conventional methods of communication, especially for those who use non-verbal forms of communication to express their will and preferences.) (UN Draft Gen Comm. 2013)</td>
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<td>• SDM should promote and support self-advocacy</td>
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<td>• SDM must be accessible and available to all (and not be limited regarding people who need a high degree of support)</td>
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<td>• All forms of support should be based on the will and preferences of the person (and not on his/her presumed best interests)</td>
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<td>• A formal system of support (with registered supporters) should be available only for “essential and important decisions of legal relevance.” For more everyday decisions, informal support networks should be used whenever possible.</td>
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<td>• A person’s mode of communication, even if limited or non-conventional, should not be a barrier to obtaining support</td>
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Elements of an SDM regime

- Legal recognition of the support person(s) chosen by the person must be available and accessible, and the state has an obligation to facilitate the creation of support, especially for those who have are isolated or do not have access to natural supports.
- Third parties must have the ability to verify the identity of the supporter and challenge the actions of the support person if they believe he/she is not following the will/preferences of the person.
- Lack of resources cannot be a barrier to using support, and the State must make sure supports are available at no or nominal cost to the person.

Elements of an SDM regime

- Support in decision making (or the need for it) cannot be used to deny other fundamental rights, such as voting, reproductive rights, parental rights, etc.
- The person must have the right to terminate or change support at any time.
- Safeguards designed to respect the will and preferences of the person must be available in all processes related to legal capacity and its exercise. (Based on UN Draft Gen Comm. 2013 & Inclusion Europe 2008)

Elements of an SDM Regime

- Per Michael Bach of Canadian Association for Community Living, Canadian SDM Models:
  - Are based on a set of guiding principles that emphasize the PWD’s autonomy, presumption of capacity and right to make decisions on an equal basis with others.
  - Recognize that a person’s intent can form the basis of a decision-making process that does not involve removal of his/her decision-making rights.
  - Acknowledge that PWDs will often need assistance in decision making through such means as interpreter assistance, facilitated communication, assistive technologies and plain language. (Dinerstein 2011-12)

SDM vs. Guardianship

- The key distinction:
  - Substitute Decision Making keeps the focus on the surrogate (guardian): the surrogate makes the decision for the PWD, even if he/she consults extensively with the person (as he/she should).
  - But—
  - Supported Decision Making keeps the focus on the PWD as the decision maker, even if the PWD needs extensive support in communicating that decision.

RIGHT TO DECISION-MAKING

- A right not only to make decisions (with support if needed) but to have those decisions recognized and honored.

Problems with Guardianship

- Even where appropriate (that is, where individual lacks capacity and there is no less restrictive alternative available), and limited, the loss of autonomy is a high price to pay for the decision-making intervention provided—“civil death.”
- Voting, participation in commerce, ability to form personal relationships all can be hindered.
- Not all guardians consult sufficiently with the [ward][incapacitated person].
- Even when they consult, they may fail to use substitute judgment standard (the decision the individual would make) and instead use a best interest standard.
- Issues of neglect, conflict of interest.
Examples of SDM

- Informal Arrangements, such as use of next friends, family members, peer support, self-advocates
- Advance directives/living wills
- Durable power of attorney
- Health care power of attorney/proxy decision-making
- Note: some would question whether the last three are supported (as opposed to surrogate) decision making because the decision-making power resides in the agent.

Examples of SDM

- Providing family integration services and supports to a parent with an intellectual disability (assist in making decisions for school children)
- Interpreting close personal contact between two people with ID to mean they wish to be intimate (even if non-verbal)
- Providing budget and money-management advice to PWD contemplating major purchase

Examples of SDM

- Naming (registering) a designated supporter who can assist in conducting financial transactions (e.g., opening and using a bank account), or making a decision regarding a one-time investment (e.g., whether to put resources into a special needs trust)
- Having a designated supporter serve as “interpreter” between health care providers and the PWD (providing a basis for giving informed consent)—E.g., “cardiologist performing an electrocardiogram” becomes “heart doctor wants to tape some wires to you that will produce squiggly lines on machine paper”

Jurisdictions that have adopted SDM

- Canada
- British Columbia, Representation Agreements
- Other provinces
- Australia
- Sweden
- Parts of Germany
- Norway
- More recently—Czech Republic, Bulgaria

Why is SDM Gaining Traction Now?

- UN CRPD Article 12 (2006; 2008)
- CRPD Committee’s Concluding Observations
- Draft General Comment on Article 12
- Comments on DGC
- Other UN bodies (UN High Commissioner for Human Rights (2009), Special Rapporteur on Torture (2013-14)
- Court Decisions—International, US
- Agency, Legislative action
- Academic Commentary

CRPD Article 12

- Article 12, Equal Recognition Before the Law:
  - 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
  - 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
  - 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
Status of CRPD in US

- 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)
- Awaiting action in Committee and in full Senate

CRPD Article 12

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

Cases

- European Court of Human Rights
- Inter-American System (2011)
- US Courts:

Status of the CRPD

- The Least We Can Do
- FEB. 19, 2014
- NYT
- Gail Collins

Can we talk about the United Nations? I know, I know. But give me a minute. We don’t do this very often. It looks as if the Senate is going to fail to ratify the U.N. treaty on the rights of people with disabilities this year. There are, of course, tons of things the Senate is going to fail to tackle between now and the fall elections. You name it, they’re prepared to not do it.

But this treaty is kind of special. It’s based on our very own Americans With Disabilities Act. It’s an international agreement in which the rest of the world basically promises to behave more like the United States. How could anything go wrong with that?

Hahahaha . . .

CRPD Article 12

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

Agency Action

- District of Columbia City Council (2013-2014)
- District of Columbia Public Schools Transfer of Educational Rights Policy (2013)
Academic Commentary

- Bach & Kerzner
- Dhanda
- Dinerstein
- Glen
- Kanter
- Kohn et al.
- Pathare & Shields
- Perlin
- Quinn
- Salzman

Potential Difficulties and Possible Solutions

- How does one make sure that the supporter does not take advantage of the PWD, or in fact is making the decision rather than assisting the PWD?—What safeguards will work?
- How does one provide protection for people in the community interacting with PWDs using support that the decisions they make will be honored and not challenged later? What standard should be used to protect these “gate-keepers”?

Potential Difficulties and Possible Solutions

- How does one discern the will and preferences of PWDs who have very limited communication skills—and life experiences?
- How does one provide support for PWDs who do not have family or friends in their lives (natural supports) to assist them? If a State or locality provides a group of (trained) individuals available to serve as supporters, how does one assure that they will spend the time needed to get to know the PWD? Can we avoid some of the problems associated with public guardianship regimes?

Potential Difficulties and Possible Solutions

- Is there any remaining concern with safety/protection? That is, is there ever a case where it would be appropriate to override the person’s decision, made with or without support?
- How do we assure that those who interact with families of PWDs—school officials, health care personnel (doctors), friends—will know enough about SDM and value it to stop counseling guardianship as the only alternative for the PWD or family?

Potential Difficulties and Possible Solutions

- Is there sufficient research support for the proposition that SDM is “better” than substituted decision making (Kohn et al.; Pathare & Shields)? How would we define better? Is it an outcome- or process-based determination? Is this even the right question to ask?
- How do we make sure that PWDs, from a young age, are trained to make decisions and to make effective use of support (at their choosing)?

References

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• Kristin Booth Glen, Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship, and Beyond, 40 Colum. Human Rts. L. Rev. 93 (2011)

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