

Supported Decision Making for Adults with Cognitive Impairments

04a Conference

11/18/15

Part 2



**Disability
Rights** OHIO

We have the
legal right of way.

The Rise of Supported Decision Making



- “New” concept growing in recognition as an alternative to guardianship
- Brought about by 2 events globally:
 - Adoption by the U.N. of the International Convention on the Rights of Persons with Disabilities (2006)
 - Overuse/misuse of substituted decision making schemes, like guardianship
- In the U.S., the Jenny Hatch case garnered a lot of attention on supported decision making

Article 12, CRPD



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.**
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.
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 equal 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.

Overuse/Misuse of Guardianships



- Since 1995, placement of adults under guardianship has tripled. (Jameson, et al. 2015)
- Despite the fact that guardianships are supposed to be imposed only as a last resort when no LRA's are available, research shows that full guardianships are the most commonly recommended course of action by professionals. (Jameson, et al. 2015)
 - SDM is the least recommended
 - Regardless of who made recommendation or what the person's disability is
- Columbus Dispatch's *Unguarded* series

U.S. - Jenny Hatch case (Virginia, 2013)



- Young woman, aged 29, with Down Syndrome
- Had worked nearly 5 years at thrift store. Lived independently in an apartment with a friend/roommate.
- Active in community – went to church, had friends, cell phone, computer, etc.
- SSI, Medicaid HCBS waiver

Jenny Hatch case, continued



- Parents filed to become her guardian after series of events
 - Jenny was injured in a bicycling accident
 - Friend lost the apartment, nowhere to go
 - Thrift store owners offered to take her in; her parents wanted her to live in a group home
- Temporary guardianship awarded to parents
 - Moved her to group home
 - Jenny was miserable

Jenny Hatch case, continued



- Litigation lasted 1 year, went to trial
- Evidence presented that Jenny was capable of making decisions, with support
- Judge ordered:
 - temporary, limited guardianship
 - appointed thrift store owners as guardians
 - guardianship was to terminate after 1 year
 - guardians ordered to make decisions based on the decision Jenny would make, not “best interests”
 - Supported Decision Making to be used following termination of guardianship

Why does it matter?



- Guardianship = Civil death penalty
- “The typical ward has fewer rights than the typical convicted felon.....By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen.” (House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper))

Why does it matter?



- Learned helplessness, low self-esteem, depression for persons under guardianship
- Increased self-determination, autonomy and empowerment linked to positive physical and psychological outcomes, better quality of life (Kohn, et al., 2013, p.1127)
- For aging population in particular – **DIGNITY!!!!**

What is Supported Decision Making?



- SDM is a process by which a person with a disability uses a series of relationships, practices, arrangements and agreements to assist the person in making and communicating to others decisions about the person's life without the need for a guardianship. (Dinerstein 2012, p.10; Blanck & Martinis 2015)

How is SDM different from guardianship?



- Although needing assistance in understanding and making decisions, the ultimate choice rests with the person with a disability.
- Under guardianship, the guardian has the ultimate decision (substituted decision making v. supported decision making)
- Under SDM, person with a disability **retains legal capacity** (goes beyond just making choices)
- SDM recognizes that the ability to make decisions is a continuum, not a Yes/No

Criticisms/Barriers



- Needs more research
- Safeguards and protection from abuse
- What if bankers, doctors, etc. refuse?
- What if someone doesn't have any family/friends/trusted persons?

**SDM doesn't really work
for aging population,
right?**



•WRONG!

SDM for the aging



- Preserves dignity
- Increase supports as needed until the person truly reaches the point where he/she can't make a decision at all
- Idea of making the decision that the person would have made if had capacity works well here

A guardianship is already in place...so we can't do



SDM, right?

- NO!!! Even under an existing guardianship, supported decision making can still be used
- In fact, many of the principles of SDM go hand in hand with duties of guardian under new Rule of Super. 66.09
 - Least restrictive, most normalizing decisions
 - Person-centered planning
 - Promoting self-reliance and independence

Sounds great!! Let's do SDM!!



- Umm.....how do we do supported decision making?
- Actually, all of us engage in supported decision making every day!

Multiple SDM Models



- Small, informal circle of support (1 or 2 family members or friends)
- Team/network of support (family, friends, providers, case managers)
- Micro Board
- Supported decision making agreements
- Combination
- There is not 1 way to implement SDM – it should be individualized

Does Ohio recognize Supported Decision Making?



- No formal recognition yet (e.g. not in statute or administrative code)
- But, doesn't mean can't use SDM! In fact, principles of SDM are consistent with existing laws
 - ADA and *Olmstead v. L.C.* decision
 - Rehabilitation Act of 1973
 - DD Bill of Rights
 - Many states' guardianship laws (including Ohio) require consideration of less restrictive alternatives before ordering a guardianship

Other Examples



- *In re Peery* case (PA 1999) – person cannot be deemed incapacitated for purpose of guardianship where the impairment is counterbalanced by friends or family or other support
- *In re Guardianship of Dameris* case (NY 2012)
- Texas (2015)
 - Formally recognizes and defines SDM as an alternative to guardianship (TX Estates Code § 1357.002(3))
 - Sample SDM agreement
- Massachusetts pilot program (ongoing)
- Talk of additional pilot programs in other states

Resources



- The Jenny Hatch Justice Project
 - <http://jennyhatchjusticeproject.org/>
- National Resource Center for Supported Decision-Making
 - <http://supporteddecisionmaking.org/>
- Texas Council for Developmental Disabilities
 - <http://www.tcdd.texas.gov/resources/guardianship-alternatives/supported-decision-making/>

Resources



- Center for Public Representation
 - <http://www.centerforpublicrep.org/litigation-and-major-cases/supported-decision-making>
- National Guardianship Association
 - http://www.guardianship.org/documents/NGA_Policy_Statement_052016.pdf