

How Supported Decision-Making can Promote Integration of People with Disabilities



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What is Supported Decision Making?

- System of supporting an individual with a disability to make his or her own choices
- May include assistance with gathering information, understanding options, and communicating with third parties
- Level of support may vary with level of need or importance of decision

We All Need Support!

- Nobody can make all their own decisions without “support” and advice
- People may get decision-making support from:

- Doctors
- Financial advisors, agents
- Lawyers
- Counselors
- Informational materials (online or elsewhere)
- Family and friends
- Clergy
- Support groups



President Obama and his support team

People with ID/DD Can Face Additional Challenges

- Difficulty understanding and remembering advice and information, or need for cognitive supports (e.g., visual explanations, simplified materials)
- Difficulty communicating information or decisions, or need for communication supports (e.g., AAC, written communication)
- Need for support to learn and carry out decision-related tasks (e.g., following health care regimen, balancing checkbook, navigating neighborhood)
- Lack of accessible information

Supported vs. Substituted Decisionmaking

Supported Decisionmaking

- Individual makes own decisions (with support)
- Individual decides who will provide support
- Level of support may vary according to situational factors

Substituted Decisionmaking

- Another person makes decisions for the individual
- Individual may not have opportunity to decide who will provide support
- Individual loses legal capacity to act independently across entire domain



A word cloud containing the following terms: rights, equality, human, ability, self-determination, practice, employment, society, progress, policy, research, perspectives, empowerment, and community.

Inclusion

The eJournal of the American Association
on Intellectual and Developmental Disabilities
aidd.org

Unjustified Isolation Is Discrimination: The *Olmstead* Case Against Overbroad and Undue Organizational and Public Guardianship

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Isolating Effects of Guardianship

In guardianship:

- Person with disability cannot make decisions without approval of guardian
- People with disabilities become “disconnected” from decision process and fail to gain – or may even lose – decision-making skills
- People with disabilities may be “constructively isolated” from community due to inability to enter into contracts, find housing, see doctor, or go shopping without guardian. - Leslie Salzman

More Isolating Effects of Guardianship

In guardianship:

- Challenges to guardian's decision and/or resolution of conflicts among family members require lengthy court process
 - If person with disability lacks assistance with this process, a challenge may not be possible at all
- Crowded dockets -> Limited court oversight
- Courts often avoid “limited” guardianships – even though they're supposed to favor them – because they want guardians to have as much authority as possible
 - Will assume that limited guardians will eventually come back to court seeking additional authority, adding burden to court docket

Public Guardianships: Special Problems

- Guardians with multiple wards may opt for “one size fits all” approach to decisionmaking
- Guardians do not have personal relationship with ward, may face communication barriers, may lack background information about ward’s preferences and personality

Example: Washington State

- Professional guardians tried to “bill” wards for the time they spent advocating against *Olmstead* enforcement
- Court denied payment because there had been no individualized determination that this advocacy was in the “individualized best interest” of each ward.
- Guardians represented dozens of individuals at a time.
- *In re Guardianship of Lamb*, 265 P.3d 876, 877 (Wash. 2011)(en banc).

Long-Term Consequences of Presumed Incompetence

- Inadequate focus on *building* skills that the person doesn't already have – especially in preparation for transition to adulthood
- Third parties may speak directly to support persons instead of including people with ID/DD in conversations about their own lives
- Doctors may refuse treatment to people with ID/DD who don't have a guardian, out of fear that people with ID/DD can't provide “informed consent” to own care
- Landlords, banks, car dealers, etc. may not recognize person's ability to sign contract without help from guardian, fearing it will be voided

How SDM helps

- Centers person with a disability in decision-making process
- Tailors support to amount needed
- Helps build decision-making experience and skills
- Requires supporters to commit to interactive process
- Holds supporters accountable to person with disability

Case Study: Jenny Hatch

- Jenny lived with her friends, Jim, and Kelly, and worked for more than minimum wage at their thrift store
- Due to her placement under temporary guardianship, she was forced to live in group home far from friends, and work in the group home's sheltered workshop
- Quality Trust successfully fought for transition to SDM – she's now back at home and at work.



Autonomy *with* Support

- Under guardianship model, autonomy of a person with cognitive or intellectual disability must be limited to protect the person from exploitation, manipulation, or “bad choices”
- Early civil libertarian critiques focused on imposing guardianship only when a person is “truly unable” to make decisions independently
- *Supported* decision making acknowledges need for support while preserving autonomy

How to Make SDM Work for Everyone?

Reforms across multiple systems:

- **Courts:** change laws to favor supported decisionmaking over guardianship
- **Support Professionals:** stop “guardianship pipeline”
- **Service Systems:** ensure that people have actual access to decision-making supports
- **Third Parties:** make sure doctors, landlords, etc. understand SDM; provide certainty that acting consistently with SDM will result in enforceable contracts/health care decisions.

Implications for HCBS

- Recent regulations require person-centered planning process for HCBS – including for people in guardianship
- Settings regulations also require integration, including meaningful opportunities to make choices, arrange schedule

Facilitating SDM with HCBS

- Use HCBS services to support decisionmaking – both everyday decisions (e.g., about daily schedule and taking medications) and long-term ones (e.g., helping people go to bank, manage budget, manage health care)
- Avoid HCBS system becoming “pipeline” into guardianship.

Service Systems: Challenges

- Many people with disabilities unable to access Medicaid-funded home and community-based services due to long waiting lists
- Even for people enrolled in HCBS, decision-making support is not always integrated into service package

Policy Responses: Service Systems

- Recognition that guardianship has *Olmstead* implications
- For example, states that provide “professional” guardianship services should also provide decisionmaking support services
- Increased recognition of SDM in HCBS packages, including through new person-centered planning requirements

Supported Decision-Making Legislation

- ASAN developed model legislation recognizing Supported Health Care Decision-Making Agreements, a new type of agreement designed to meet the needs of people with significant support needs
- Developed in collaboration with Quality Trust for Individuals with Disabilities – a D.C.-based non-profit focusing on self-determination for people with significant disabilities
- In process of creating broader legislation for financial, other decision-making



Nothing about us without us!

MODEL LEGISLATION

Developed in collaboration with Quality Trust

AN ACT RELATING TO THE RECOGNITION OF
A SUPPORTED HEALTH CARE DECISION-MAKING AGREEMENT
FOR ADULTS WITH DISABILITIES

<http://autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/>

Benefits of Supported Decision-Making Legislation

- Gives individuals clear option to create recognized support relationship
- Avoids costly, traumatic, and/or lengthy court proceedings
- Individuals are *protected* from many forms of abuse or exploitation because they retain capacity to go against wishes of support person

ASAN's Model Legislation

- Allows supported decision-making arrangements in health care contexts
- Supporters can access health information, communicate with health providers under exception to HIPAA
- Includes standard form in simple language
- Provides protection to doctors who follow, in good faith, directions made through supported decision-making

How We Designed the Model Legislation

- Reviewed published guardianship decisions in past decade to identify why courts awarded guardianship in contested cases
 - Major factors were perceived lack of acceptable alternatives, desire to make sure person is “taken care of”
- Analyzed supported decision-making legislation in other countries, including Canada, Sweden, U.K.

Major Goals

- Accessibility to people with limited financial, educational resources
 - Litigating a guardianship case can cost thousands of dollars
 - Most Americans lack ready access to legal representation
 - Court proceedings may take a long time
- Availability to people with significant cognitive impairments
 - Process must be understandable
 - Agreement must be valid even if person has support needs
- Preservation of decision-making rights
 - Goal is self-determination
 - “Private” agreements that involve potential relinquishment of rights give rise to potential for abuse

Other Considerations

- Alleviating liability concerns that may contribute to discriminatory denial of care for people with ID/DD who don't have guardian
- Respecting diversity in choice of supporter
- Avoiding conflict of interest
- Preventing abuse / providing clear process for reporting abuse
- Preventing fraud

Overview of Legislation

- Allows person with ID/DD to execute Supported Health Care Decision-Making Agreement, naming a supporter
- Supporter is authorized to assist in decision-making, including communicating with / facilitating communication with doctors, obtaining records, making appointments, accompanying person to appointments, assisting in daily health routines
- Person with disability makes all final decisions
- Decision made with support can count as “informed consent”

Preventing Fraud

- “Private” agreement eliminates need for court involvement (in most cases) – this is necessary to ensure access
- Agreement must be witnessed and notarized, reducing potential for fraud
 - Many similarly high-stakes agreements, like powers of attorney, often have similar protections (depending on state)
- Person with disability must actively participate in decision-making; supporter cannot fulfill most support functions without person’s knowledge

Minimizing Conflicts of Interest

- Conflict of interest provisions restrict who may serve as supporter
 - Treating physicians, people with major financial conflicts of interest, and staff in institutional settings cannot serve as supporters
- Conflict of interest provisions designed to ensure that spouses, parents, friends, and home support workers are not automatically excluded from serving as supporters

Ensuring Availability to People with Significant Disabilities

- Agreement is valid even if person with ID/DD is considered unable to execute a valid power of attorney or provide “informed consent” without support
- This is necessary because otherwise people would be forced into unnecessary guardianship or would risk denial of care
- Agreement preserves individual’s right to make final decisions and to terminate agreement – unlike powers of attorney which can allow agents to make “unilateral” decisions for the individual. This ensures that people are protected in the case of an unforeseen problem with the supporter.

Preserving Doctors' Role

- Health providers retain ability to exercise professional judgment regarding treatment
- Do not have to provide care that they feel is harmful or not medically beneficial
- Do not have to provide care if they believe that the supporter hasn't conveyed important information to the individual, or suspect consent was obtained through abuse or coercion

Solving Disputes and Preventing Abuse

- Doctors or others may report suspected abuse to adult protective services agency
 - These agencies often investigate complaints faster than guardianship courts can hold hearings on challenges of guardians' conduct
 - Substantiated complaints will result in removal of supporter
 - In states with mandatory reporting laws, reports are mandatory

Next Steps

- No state has passed legislation that recognized supported decision-making agreements
- Some courts, including ones in New York and Virginia, recognize that people with ID/DD can make decisions with support – but these relationships are often informal and lack clear definitions
- The form in ASAN’s model legislation can be used to help people express their intention to form a supported decision-making relationship – but may not be legally recognized or binding
- Advocates can ask their state legislators to pass legislation recognizing supported decision-making agreements
 - The model legislation may serve as a “starting point”