The Next Generation of Freedom and Self-Determination: Moving Support Decision-Making from Theory to Practice

Supported Decision-Making and Medicaid, Home and Community Based Services Settings Final Rule

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Barbara Brent
Director of State Policy, NASDDDS

Samantha Crane
Director of Public Policy, ASAN

Jonathan Martinis
Legal Director, Quality Trust for Individuals with Disabilities

Moving Supported Decision-Making from Theory to Practice: Medical Decision-Making and Planning

Jonathan Martinis
Legal Director, Quality Trust for Individuals with Disabilities
Project Director, National Resource Center for Supported Decision-Making

Article of Faith 1

"[P]hysical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society"

The Americans with Disabilities Act, 42 U.S.C. 12101

Article of Faith 2

People with disabilities who have greater self-determination – more control over their lives - are:

- Healthier
- More likely to be employed at higher wages
- More integrated in their communities
- Better able to identify and resist abuse

(Khemka, Hickson, & Reynolds, 2005; Wehmeyer, Kelchner, & Reynolds, 1996; Wehmeyer & Schwartz, 1998).

Article of Faith 3

Guardianship, by definition, decreases self determination and can lead to a "significant negative impact on. . . physical and mental health, longevity, ability to function, and reports of subjective well-being."

(Wright, 2010)

Article of Faith 4

Supported Decision-Making is:

"a recognized alternative to guardianship through which people . . . use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the "need" for a guardian."

(Blanck & Martinis, 2015).

Article of Faith 5

"Supported Decision-Making has the potential to increase the self-determination of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment, and community integration"

(Blanck & Martinis, 2015)

US Surgeon General Report

People with Disabilities have more medical conditions, yet are more often poorly diagnosed [and] over/under treated

(Office of the Surgeon General "The surgeon general's call to action to improve the health and wellness of persons with disabilities." (2005)).

Numbers

In a recent survey, 10% of people under guardianship or who sought guardianship for someone identified a medical professional as the person who first recommended it.

(Jameson, et al (in presss))

Think About It

- "Who will sign the consent form?"
- "Who is responsible for payment?"

"Informed Consent"

Like "Capacity" is to guardianship, it is the lynchpin of self-determination in medical care

Three Key Parts:

- Information to the person
- Understanding by the person
- Choice by the person

As With EVERY Decision

- Assistance can be provided to help individual make medical decisions:

  "Explain that to me in English"

- Ability to make decisions is a continuum. A person may be able to make some but not others

  Consenting to a flu shot is not the same as completing a Credit Default Swap

THEREFORE

There is a need to show medical personnel that alternatives like Supported Decision-Making are:

- Flexible
- Immediate
- Improve Dr-Patient communication and collaboration
- Increase the role of family, friends, and people close to the patient

HOW?

Think about a HIPAA release

What does it do?

THINK ABOUT IT?

What is Supported Decision-Making other than an exchange of information?

So why not use (or slightly modify) a HIPAA release to enable Supported Decision-Making?

Forms

Easy as adding language "and for decision-making purposes" in HIPAA release

Of make up your own form.

Or use models, like http://autisticadvocacy.org/wp-content/uploads/2014/07/ASAN-Supported-Decisionmaking-Model-Legislature.pdf

Advocacy Tips

"But That Violates Confidentiality"

- Not if the person gives permission
- It's the same as using an interpreter or a HIPAA release

Other Options

Advanced Directive or Power of Attorney

- Patient designates someone to make decisions for him/her as opposed to guardian
- Does not require patient have capacity to give informed consent to treatment, but must have capacity to enter into Directive

Sample Language

My agent will work with me to make decisions and give me the support I need and want to make my own health care decisions. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make health care decisions for me, my agent will provide support to make sure I am able to make health care decisions to the maximum of my ability, with me being the final decision maker.

Person Centered Planning

- A process for planning receipt of services and supports
- Based on person's preferences and choices
- Builds on person's desire and ability to engage in and direct process
- Involves family members, friends, professionals, supporters and others as requested by the person

Person Centered Planning

What is:

- Important TO the Person
- Important FOR the Person

Where the Person is and where the Person wants to be

- What needs to change and what needs to stay the same to get there

Doesn't That Sound Like

Like Supported Decision Making?

Or a "Student Led IEP"?
Or "Informed Choice" in Vocational Rehabilitation?

IT'S A PARADIGM NOT A PROCESS!

Good Thing, Because

It's REQUIRED in Medicaid HCBS Waiver programs - **Final Rules CMS 2249-F and CMS 2296-F**

Services MUST:

- Be Driven by the person
- Include people chosen by the person
- Occur at times/locations convenient to the person

It Happens

Guardianship happens when people can't "take care of themselves in a manner that society believes is appropriate."

(Kapp, 1999).

Isolation

When people are not given the opportunity to make their own decisions:

- "Diminish[es] the individual's opportunities to test his or her abilities."
- The "disuse of decision-making powers" may lead to further decline in the individual's capabilities, leading to further isolation and loss of abilities

(Salzman, 2010, p. 170).

In Other Words

Decision-Making:

- Is a skill
- Can change over time – improve or get worse
- Is individualized - different people use different methods

The Challenge Out There

- In DC….
  - 70% of people served by Department on Disability Services have a guardian or substitute decision-maker.
  - 13% are identified as being able to make their own decision
- Nationally….
  - According to the CQL database, only one-half or fewer of the over 8,100 people reviewed were exercising choices about home, work, goals or services in a way that was meaningful to them.

Lost Generation

Number of adults under guardianship has **TRIPLED** since 1995 (Schmidt, 1995; Reynolds, 2002; Uekert & Van Duizend, 2011).

Our Challenge

Overcoming the continuing public perception that Older Adults and People with Disabilities need "protection, not rights."

Dinerstein, R. (2012).

If We Do That

Article of Faith 1 becomes the Genuine Article:

Older Adults and People with Disabilities CAN and DO "fully participate in all aspects of society"

More Information and Contact

National Resource Center for Supported Decision-Making Website:
SupportedDecisionMaking.Org

Jonathan Martinis, Legal Director
JMartinis@DCQualityTrust.Org

About This Project

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Supported Decision Making

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IDEAS AND CONSIDERATIONS WITHIN STATE I/DD AGENCIE & NEW HCBS REGULATIONS

What is a HCBS Waiver??

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- A waiver means that the regular rules are "waived", that is not applied
- The HCBS waiver began in 1981 as a means to correct the "institutional bias" of Medicaid funding
- The "bias" is that individuals could get support services while institutionalized, but if they wanted to return to the community they could not get similar services

****Thanks Robin Cooper for making this easy to explain!*

What is a HCBS Waiver??

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- Section 1915 (c) of the Social Security Act was changed to allow states to ask for waivers of existing Medicaid regulation
- The idea is that states can now use the Medicaid money for community services that would have been used for the person in an institution
- Thus, getting HCBS waiver services is tied to institutional eligibility

* *Thanks Robin!*

Institution/HBCS link

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- This does NOT mean you have to go to an institution or want to go to an institution—just that you could be eligible for services in an institution
- There are some new authorities in Medicaid that don't "link" these two things together-but most do.

Understanding our history can help move forward:

This put self determination and supported decision making in a rough place to start----presuming that a person is at risk of institutionalization to qualify for the community creates some work on all of our parts to show how that people can and should make decisions.

Mandatory monitoring health and safety includes under CMS includes:

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- State oversight of the service system and providers through visits to people and providers
- Getting information from waiver participants about how they like their services
- A formal system to prevent, report and resolve instances of abuse or neglect
- *Given these- what are some ideas to INCREASE supported decision making at the systems level?*

NEW HCBS rules: The big deal stuff

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- HCB Settings Character
  - What is NOT community
  - What is likely not community
  - What is community
- Person-centered planning
  - Codifies requirements
- Conflict-free case management
  - Was just in guidance, now it is in rule:

https:www.federalregister.gov/r/0938-AO53

Before we define HCB Settings character..

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- Settings that are NOT Home and Community-based:
  - Nursing facility
  - Institution for mental diseases (IMD)
  - Intermediate care facility for individuals with intellectual disabilities (ICF/IID)
  - Hospital

Settings PRESUMED not to Be Home And Community-based

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- Settings in a publicly or privately-owned facility providing inpatient treatment
- Settings on grounds of, or adjacent to, a public institution
- Settings with the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS

Settings that isolate

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- The setting is designed specifically for people with disabilities, and often even for people with a certain type of disability.
- The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.
- The setting is designed to provide people with disabilities multiple types of services and activities on-site, including housing, day services, medical, behavioral and therapeutic services, and/or social and recreational activities.

Settings that isolate…

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- People in the setting have limited, if any, interaction with the broader community.
- Settings that use/authorize interventions/restrictions that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).

Source: CMS guidance: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf

HCBS setting requirements

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- Is integrated in and supports access to the greater community
- Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources
- Ensures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid home and community-based services
- The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting

HCB setting requirements

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- Ensures an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint
- Optimizes individual initiative, autonomy, and independence in making life choices
- Facilitates individual choice regarding services and supports, and who provides them

Not Just Residential

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- **Be aware this is not just residential…the HCBS settings requirements apply to ALL HCB settings including day and pre-vocational programs….**
- CMS noted in the comments…:
  - "To the extent that the services described are provided under 1915(i) or 1915(k) (for example, residential, ***day***, or other), they must be delivered in settings that meet the HCB setting requirements as set forth in this rule. We will provide further guidance regarding applying the regulations to non-residential HCB settings."

Of **everyone** with I/DD in the US
89% of People with I/DD are Supported by Family

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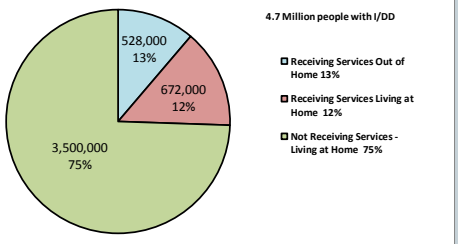

Persons with I/DD Receiving Services While Living with Family Members as a Percentage of All Persons with I/DD Receiving Services

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Data Downloaded: 10/14/14 RISP-UMINN

State	2011		State	2011		State	2011
AL	48.8%		LA	67.20%		OK	44.1%
AK	23.8%		ME	8.60%		OR	60.6%
AZ	86.4%	1	MD	22.1%		PA	57.0%
AR	34.5%		MA	DNF		RI	28.4%
CA	70.7%	3	MI	53.6%		SC	DNF
CO	51.4%		MN	50.3%		SD	31.4%
CT	53.6%		MS	DNF		TN	32.2%
DE	68.9%		MO	50.8%		TX	DNF
DC	33.4%		MT	56.1%		UT	34.3%
FL	69.9%		NE	22.3%		VT	50.8%
GA	52.4%		NV	66.9%		VA	18.8%
HI	68%		NH	25.8%		WA	65.7%
ID	DNF		NJ	71.3%	2	WV	DNF
IL	29.1%		NM	15.8%		WI	37.6%
IN	46.4%		NY	62.0%		WY	42.4%
IA	36.8%		NC	DNF		Reported US Total	56.5%
KS	34.4%		ND	30.0%			
KY	25.6%		OH	69.0%			

DNF—Did not furnish

A vision for supporting individuals & families

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Individual with Disability:

achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life

Families:

will be supported in ways that maximizes their capacity, strengths and unique abilities **so they can best support, nurture, love and facilitate……**

Birth--Early Child--School--Transition----------Adulthood----------Aging

*National Definition for "Supporting Families" (2011 Wingspread)

Person-centered planning

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- Conducted to reflect what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare
- Identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual
- May include whether and what services are self-directed

Written Plan Reflects

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- Setting is chosen by the individual and is integrated in, and supports full access to the greater community
- Opportunities to seek employment and work in competitive integrated settings
- Opportunity to engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS

Provider-Owned or Controlled Residential Settings

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- CMS has developed a set of criteria that must be met when there are "modifications" to the settings requirements for an individual
- Basically this is about any restrictions such as limiting access to food or concerns about furnishings for example
- Modifications of the additional requirements must be:
  - Supported by specific assessed need
  - Justified in the person-centered service plan
  - Documented in the person-centered service plan

???What can be done here to support decision making in order tor reduce restrictions?

Case Management and Conflict of Interest

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- "Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the person-centered service plan,
- [Providers may be allowed if] the State demonstrates that the only willing and qualified entity to provide case management and/or develop person- centered service plans in a geographic area also provides HCBS.
- In these cases, the State must devise conflict of interest protections …which must be approved by CMS. Individuals must be provided with a clear and accessible alternative dispute resolution process."

42 CFR §441.301

Increasing Decision-Making

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- **Are we doing what is important to the person?**
  Activities; people; routines; possessions; experiences
- **Are we doing what is important for the person?**
  Is the person healthy and safe?
- **Is the person happy with life?**

How is this being measured in a way meaningful to the person and their team ,not just the system?

Person-centered planning**

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- The person-centered planning process is driven by the individual
- Includes people chosen by the individual
- Offers choices to the individual regarding services and supports the individual receives and from whom
- Provides method to request updates

**Language taken directly from the new rules.

Plans do not match desire to work…

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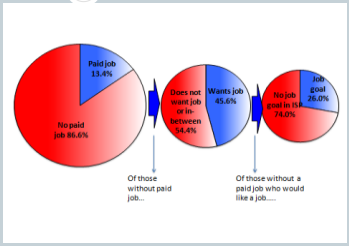
- 45.6%)of people interviewed who were reported to not have a paid job in the community indicated that they would like to have one.
- Only 13.1% of those without a community job had employment identified as a goal in their individual service plans (ISP).
- Only 26.0% of people who did not have a job and stated that they would like work had this goal documented in their service plans.



http://www.nationalcoreindicators.org/upload/core-indicators/update_on_data_brief_type_of_employment_-_final.pdf

NCI System Performance Measures

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Individual Outcomes

- Employment
- Community Participation
- Choice & Decision making
- Personal Relationships

Family Outcomes

- Choice and Control
- Family Involvement
- Information & Planning
- Access, community connections

Health, Welfare, System

- Health and Welfare
- Respect for Rights
- Medications
- Safety
- Service Coordination
- Staff Stability

The new rules…

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- Give us a LOT to think about
- Probably a LOT to do
- But the rules can potentially represent an incredible opportunity to bring our supports and services closer to what we aspire to in our system values and vision statements….

Decision-Making in Health Care Contexts: Supporting People with ID/DD

Samantha Crane, J.D., Policy Director
The Autistic Self Advocacy Network
2013 H St. 7th Floor • Washington, DC 20035
Voice: (202) 596-1056
www.autisticadvocacy.org

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Acknowledgments

The Special Hope Foundation

Quality Trust for Individuals with Disabilities

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What is Health Care Decision-Making?

- Not just deciding between different treatment options, but also deciding:
  - When to see a doctor
  - Which doctor to see
  - When to seek a second opinion
  - Whether to seek treatment/follow recommendations
  - Whether to ask for a different treatment strategy

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What is Health Care Decision-Making?

- Decision-making can also include day-to-day decisions like:
  - Taking routine medications
  - Making routine appointments
  - Making follow-up appointments
  - Attending physical therapy or other regularly scheduled health visits
  - Maintaining own medical records

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We All Need Support!

- Nobody can make all their own medical decisions without "support" and advice – not even doctors themselves!
- You may get decision-making support from:
  - Your doctor
  - Your pharmacist
  - Informational materials (online or elsewhere)
  - Close family and friends
  - Support groups for people with health concerns

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People with ID/DD Can Face Additional Challenges

- Difficulty understanding and remembering health-related advice and information, or need for cognitive supports (e.g., visual explanations, simplified materials)
- Difficulty communicating information to doctors and health professionals, or need for communication supports (e.g., AAC, written communication)
- Need for support to learn and carry out health-related tasks (e.g., taking medications regularly, administering insulin, testing blood sugar)
- Lack of access to accessible health information

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"After the age of majority, all youth deserve to be treated as adults and to experience an adult model of care."

•American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians-American Society of Internal Medicine

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Challenges to Self-Direction

- Only 40% of youth with special health needs received recommended Maternal and Child Health Bureau transition planning services
- Compared to other youth with special health care needs, youth with autism spectrum diagnoses are only two-thirds as likely to be encouraged to take responsibility for their own health care when they become adults
- Others with developmental or psychiatric disabilities are also unlikely to be encouraged to take on adult roles

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Negative Assumptions Can Hurt People with Disabilities

- Need for support is interpreted as lack of ability to make decisions
- Health professionals assume that people with ID/DD have, or should have, a guardian to make decisions for them

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Consequences of "Presuming Incompetence"

- Inadequate focus on *building* skills that the person doesn't already have – especially in preparation for transition to adulthood
- Doctors may speak directly to support persons instead of including people with ID/DD in conversations about their own health care
- 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

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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

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Supported Decision-Making and Health Care

- Supports those with difficulty communicating, understanding health decisions, or adhering to medical advice
- Person with ID/DD retains ability to make final decisions about health care
- Supporters are trusted individuals and may include family, friends, spouse, or direct care worker

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Autonomy *with* Support

- Substituted decision-making model was based on perceived need to protect person with disability from exploitation, manipulation, or "bad choices"
- Early civil libertarian critiques focused on avoiding guardianship when individual is not "truly disabled"
- *Supported* decision making acknowledges need for support while preserving autonomy

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Examples of Supported Decision-Making Strategies

- Accompany person to doctor's appointments to help facilitate effective communication
  - May include "translating" information, prompting person with ID/DD, and/or helping manage anxiety
- Helping person understand options and make decisions that serve their priorities and values
- Reminding person to make appointments (or serving as an intermediary in order to make appointments
- Assistance with health monitoring, deciding when to see a doctor
- Direct assistance with treatment routines like medication or insulin
- Keeping health records organized

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Implementing Supported Decision-Making

- May be informal (e.g., accompanying person to doctor's office, reminders to take medication)
  - Americans with Disabilities Act requires doctors to make "reasonable modifications" to policies, including policies against allowing patients to bring supporters into examination rooms
  - Supporters may be kept out of room when doctor is asking questions about abuse, or when the room must be "sterile" (e.g., an operating room)

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Implementing Supported Decision-Making

- May be formalized through existing "support" documents
  - HIPAA Release: person with ID/DD signs a form allowing doctors or health care workers to speak with supporter(s)
  - Health Care Power of Attorney: person with ID/DD authorizes supporter(s) to make health care decisions in emergencies or other situations where they can't decide for themselves
  - Health Care Directive: person with ID/DD expresses wishes regarding potential future care (e.g., resuscitation, administration of specific medications, withdrawal of life-sustaining care)

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Guardianship or Supported Decision-Making?

In guardianship:

- Person with disability cannot make health care decisions without approval of guardian
- People with disabilities become "disconnected" from care and fail to gain – or may even lose – decision-making skills
- Doctors may not understand scope of guardian's authority to make decisions about sterilization, withdrawal of life-sustaining treatment

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Guardianship or Supported Decision-Making?

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

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Olmstead and the Integration Mandate

- *Olmstead v. L.C.* (1999): Supreme Court held that ADA requires services to be provide in the "most integrated setting" appropriate to individuals' needs
- Leslie Salzman (Cardozo School of Law) has argued that guardianship inherently restricts individuals' access to community

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Case Study: "Dameris L."

- Woman with Intellectual Disability, living in New York, married to a man with psychosocial disabilities
- Court awarded co-guardianship to mother and husband, in part due to concerns about Dameris' ability to parent her newborn child
- Due to financial circumstances, family had to move to Pennsylvania, but couldn't do so without court approval

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Case Study: "Dameris L."

Judge Kristen Booth Glen removed guardianship, finding:

- Dameris had robust support network, including husband, mother, neighbors, extended family, and social services workers
- Dameris and husband were "far more of a partnership than … a guardian and his ward."
- With support, Dameris could parent effectively, make responsible medical decisions
- Dameris' supported decision-making arrangements were a "less restrictive alternative to the Draconian loss of liberty" of full guardianship

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Case Study: "Dameris L."

Glen found guardianship was *unconstitutional* in situations where person could live safely in community with the support of others, including "family, friends, and professionals."

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Limits of Guardianship Reform

- Previous efforts at guardianship reform focused on limiting when individuals could be placed under guardianship, and limiting the scope of guardianship
- These reforms are important, *but* people who need significant support to make health-care decisions may still be subjected to unnecessary guardianship

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Limits of Guardianship Reform

- Even when required to consider less restrictive alternatives, judges often grant guardianship, even in contested cases, because:
  - They prefer a recognized legal structure or "accountable" support person
  - They believe that people with disabilities will be exploited outside context of guardianship
  - They believe that loss of legal capacity is essential to protecting individuals from own decisions
  - Once declared disabled, the person with a disability cannot execute a valid power of attorney or other "alternative" contractual relationship

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Limits of Guardianship Reform

- Example: *Guardianship of E.L.* (N.H. 2006)
  - Judge rejected less alternative options to guardianship, stating "A power of attorney would not be sufficient because [E.L.] could cancel it."
- Example: *In re Mary J.* (N.Y. 2002)
  - Judge rejected less restrictive alternatives, such as health care proxy and power of attorney, because woman "lacked capacity" to sign them. Court awarded guardianship to two of the woman's three children, despite her clear preference to be supported by the third (who lived with her)

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Limits of Guardianship Reform

- Doctors may face liability for performing medical procedures when individual lacks "capacity" to provide informed consent, unless consent is obtained from a legal guardian
  - May face liability even if the person with disability does not object and the medical procedure is objectively beneficial and appropriate
  - For people whose families choose not to pursue guardianship, or can't afford court procedure, this can mean denial of access to necessary health care

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Limitations of Existing "Formal" Arrangements

- HIPAA releases, health care powers of attorney, and health care directives were designed to be executed by people who *do not have cognitive disabilities at the time they are signed*.
- Courts may not recognize these documents as valid if they are signed by person with significant cognitive disability
  - Doctors may fear honoring documents signed by person with cognitive disability, for fear that they will be declared invalid by court
- Health care power of attorneys often still use *substituted* decision-making principles, not supported decision-making

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A Solution: Supported Decision-Making Agreements

- 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

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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

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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

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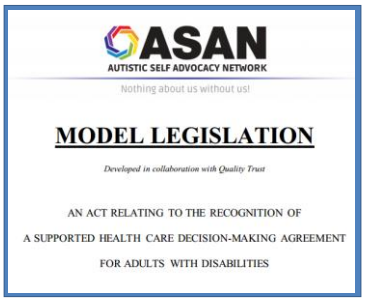

http://autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood/

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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.

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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

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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

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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"

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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

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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

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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.

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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

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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

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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"

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Questions to Consider

- CMS has made clear the intent that individuals with disabilities receiving supports and services under HCBS waivers should promote self-determination. How can individual plans improve decision-making skills so lives are more self-directed?
- Do states have an affirmative obligation to identify and help individuals with guardians to restore their decision-making authority?
- Olmstead settlements between states and the Justice Department have set goals for expanded community living and integrated community employment opportunities. What requirements might there be as well about supported decision-making?
- What can states do to increase opportunities for supported decision-making for HCBS waiver participants?
- For an individual with significant disabilities, who should they turn to for help with making informed decisions?
- Guardianship restricts community participation is a claim made by many self advocates and legal experts. What policies or practices should be changed to reduce the dependence on guardianship for decision-making?
- What examples can you offer of policy guidance for state DD agencies to promote less restrictive alternatives than guardianship?
- Will supported decision making make people more vulnerable to coercion or abuse?
- What about people who are mentally ill and don't want to take medications?
- How can waiver service providers encourage supported decision making in cases where a person already has a guardian?

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Part III: Supported Decision-Making and the ABLE Act, "Achieving Better Life Experience"

Date: June 18, 2015 | 1:00pm-2:30pm

Presenters:

- Lisa Mills, Public Policy Chair, TASH
- Allison Wohl, Executive Director, APSE
- Jonathan Martinis, Legal Director, Quality Trust for Individuals with Disabilities

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More Information and Contact

National Resource Center for Supported Decision-Making Website:
SupportedDecisionMaking.Org

Jonathan Martinis, Legal Director
JMartinis@DCQualityTrust.Org

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