

Supported Decision-Making Legislation: Why Do We Need It?

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We All Need Support!

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



President Obama and his support

team of President Obama, seen from the back, at the head of a large conference table. Members of his cabinet are also at the conference table, including John Kerry, Joe Biden, Susan Rice, and Eric Holder.

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

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**

Existing Support Tools

- **Informal**
 - Talk to a friend
 - Bring a companion to appointments
- **HIPAA Release**
- **Hiring a Consultant/Professional**
- **Power of Attorney**
- **Health Care Proxy**
- **Advance Directive**
- **Translator/Communication Aide**

Using Existing Tools in Disability Contexts

- **Power of Attorney, Health Care Proxy, etc. require "*capacity*" to execute**
- **In *uncontested* situations, third parties must assume that these documents are valid**
- **Problems when:**
 - Family disputes
 - Family/provider disputes
 - Existing guardianship/guardianship proceeding

Other Barriers to Supported Decisionmaking

- **Lack of education among families and service providers who work with people with disabilities**
- **Skepticism among judges who decide guardianship cases**
- **Failure of third parties (e.g., doctors, landlords, financial service providers) to recognize contracts signed by people with disabilities using supported decisionmaking**

Gaps in Family/Provider Education

- **Systems recommend guardianship:**
 - Schools
 - Hospitals
 - Service providers
- **Estate, family, disability lawyers also may recommend guardianship**
- **Drafting “SDM-friendly” powers of attorney may take work and creativity**

Sources of Skepticism Among Judges

- **Absence of recognized legal structure or “accountable” support person**
- **Some people with disabilities can’t execute existing “alternatives,” such as power of attorney**
- **Belief that people with disabilities will be exploited outside context of guardianship**
- **Belief that loss of legal capacity is essential to protecting individuals from own decisions**

Skepticism Among Judges: Examples

***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.”

***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

Third-Party Skepticism

- **Contract law allows voiding of contracts due to mental disability**
- **Physicians have ethical and legal duty to obtain “informed consent”**
- **Third parties may assume that a person with a known disability “needs” a guardian**

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/>

The image is of the first page of ASAN's modern legislation. At the top of the page is the ASAN logo and the text "Autistic Self Advocacy Network, Nothing about us without us!"

In the middle of the page is the text: "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"

ASAN's Model Legislation

- **Allows supported decision-making arrangements in health care contexts**
- **Available to people with significant disabilities**
- **Supporters can access health information, communicate with health providers under exception to HIPAA**
- **Person with disability makes final decisions**
- **Includes standard form in simple language**
- **Provides protection to doctors who follow, in good faith, directions made through supported decision-making - they can count as "informed consent"**

Benefits of Supported Decision-Making Legislation

- Gives individuals 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

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**

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**

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**

Finances?

- **Financial SDM raises unique concerns, especially for elderly and others with significant assets**
- **Unlike in healthcare, decisions not always mediated by professional with ethical obligations**
- **British Columbia's SDM law includes option for "monitor" separate from supporter - and restrictions on certain kinds of transactions**

State Implementation

- **In 2015, Texas passed supported decision-making legislation**
 - **ASAN model legislation incorporates key elements, but differs in some ways**
 - **Unclear how courts will interpret capacity requirement**
 - **Fewer detailed protections**
- **Some courts, including ones in New York, Massachusetts, and Virginia, recognize that people with ID/DD can make decisions with support – but these relationships are often informal and lack clear definitions**

Next Steps

- **Advocates can ask their state legislators to pass legislation recognizing supported decision-making agreements**
- **Potential models:**
 - **ASAN model legislation**
 - **Texas**
 - **British Columbia**
 - **Create your own!**

In the Meantime...

- **The supported decision-making agreement in the model legislation can still be created using special powers of attorney**
- **There still may be challenges to capacity if families are in conflict, and third parties may need to be educated about this type of agreement.**
- **National Resource Center for Supported Decisionmaking is developing a supported decision-making “forms bank”**