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# Supported Decision-Making: Planning for Medical Decision-Making

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# What Is Supported Decision-Making?

- *Supported Decision-Making*: A process by which a person with a disability gets help understanding and making their own decisions with the aid of trusted people of their choice called *supporters*
  - A person can and should pick different, multiple supporters for different decisions (e.g., Would you hire a plumber to do your interior decorating?)
  - Supported decision-making allows the person with a disability to retain control of their own lives and choices to maximum extent possible

# Supported Decision-Making in Healthcare

- *Healthcare Supported Decision-Making* allows:
  - Supporters to help the person with a disability navigate the healthcare system
  - Supporters to help explain and put in context person's health care choices
  - Person with a disability makes final decision

# Ingredients for Successful Healthcare Supported Decision-Making

- Involvement of disability-competent primary care provider as a participant in the decision-making process
- Thorough transition planning for young adults with disabilities (if person is young adult) and other training for all adults with disabilities who need it
- Presumption of competence of the person with a disability

# Ingredients for Successful Healthcare Supported Decision- Making (cont'd)

- Coordinated health care delivery models (“health home models,” etc.) which adapt to fit the patient’s specific needs
- Cognitively accessible health care services (e.g., plain language forms and documents, extra time, reduced number of steps), legal documents (HIPAA release forms, etc.), and supporter explanations of health care decisions

# Building a Circle of Support

- Supporters should be drawn from multiple types of people, including:
  - Friends
  - Family members, including spouses
  - Medical professionals, if they lack conflicts of interest
  - Support personnel, if they lack conflicts of interest
- The person with a disability should identify and choose all their supporters
- It may be beneficial to hold meetings, similar to person-centered planning, of all supporters directed by the person with a disability regarding major health care choices

# Medical Supported Decision-Making and the Law

- All people with disabilities, under the Americans with Disabilities Act and the Affordable Care Act, have the right to any “aid or service” they need to give informed consent, such as having another person with them when they go to the doctor
- Actual supported decision-making laws are pretty rare, although some states like Texas and Delaware have them



# Medical Supported Decision-Making and the Law (cont'd)

- Most states do have guardianship and conservatorship laws, which take power away from people with disabilities
- Most states have documents known as *medical advance directives* or *psychiatric advance directives* and *medical powers of attorney*

# Americans with Disabilities Act

- Titles II and III of the Americans with Disabilities Act (ADA) prohibit any public or private entity open to the public (e.g., nearly all healthcare providers) from discriminating against people with disabilities
- Discrimination includes failing to provide or allow any reasonable modifications to the service or a failure to accommodate the person with a disability
- This would include not allowing another person (the person's supporter) to help the person with a disability with their healthcare or not providing what the person needs to make healthcare decisions cognitively accessible



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# Americans with Disabilities Act (cont'd)

- A person with a disability might need to fill out a HIPAA disclosure form if they want their doctor to give their medical records to their supporter(s)
- The ADA's regulations also require all entities covered by the ADA to provide "effective communication" to people with disabilities

# Affordable Care Act

- Section 1557 of the Affordable Care Act prohibits “health programs or activities” receiving federal money from discriminating against people with disabilities
- It also requires them to establish “effective communication” with people with disabilities in a manner similar to that in the ADA’s regulations...
  - ...and provide the person with a disability with any aids or services necessary to establish effective communication

# Health Insurance Portability and Accountability Act (HIPAA)

- These forms authorize the doctor or healthcare provider to disclose a person's "protected health information" --- doctor's visit records, medical reports, x-rays, etc. --- to another person
- A person with a disability would not need to sign a HIPAA form if the supporter is in the room with them, but they would need to sign it for the supporter to have a conversation over the phone with their doctor

# The Two Non-Guardianship Formal Support Arrangements You Can Make in Most States...

- You can make a:
  - *Durable medical power of attorney or health care proxy*
  - *Medical or psychiatric advance directive*
- In a few states, you can also create a formal supported decision-making arrangement

# Medical and Psychiatric Advance Directives

- These help a person with a disability express their wishes if they have a health or mental health crisis
- They typically describe in detail the treatments the person does and doesn't want
- They are not legally binding, but many doctors respect the wishes outlined on one
- Similar documents may also help people with communication-related disabilities who do know what they want, but can't express it immediately

# Durable Medical Powers of Attorney/Health Care Proxies

- These allow a person who cannot make decisions at a particular time to assign someone to make decisions for them in their place
- They can be revoked at any time so that the person can make decisions again
- They do give someone else the ability to make decisions for the person with a disability, even if the person can revoke it
- They are considered legally binding in practically every state
- States may have different requirements for signing



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# Supported Decision-Making Agreements

- Even though they are not binding in most states, it may still be helpful to create a formal supported decision-making agreement for many people with disabilities
- A formal agreement will:
  - Show the person's health care provider that they are using supported decision-making
  - Help determine what the person's supporters can and can't do
- Examples of SDM agreements:  
<http://supporteddecisionmaking.org/sites/default/files/sample-supported-decision-making-model-agreements.pdf>

# Resources

- ASAN's Toolkit on Health Care and the Transition to Adulthood:  
<http://autisticadvocacy.org/policy/toolkits/healthtransition/>
- ASAN's Right to Make Choices plain language toolkit:  
<http://autisticadvocacy.org/2016/02/the-right-to-make-choices-new-resource-on-supported-decision-making/>

# Resources

- National Resource Center for Supported Decision-Making:  
<http://supporteddecisionmaking.org/>
- The Arc's Center for Future Planning:  
<https://futureplanning.thearc.org/pages/learn/future-planning-101>
- Supported Decision-Making Resource Library on the ACLU:  
<https://www.aclu.org/other/supported-decision-making-resource-library>

# Supported Decision-Making: Making It Work!



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# What Is a Decision?

- Decision: Understand options; risks/benefits of each; weigh them against each other; communicate a choice
- Capacity fluctuates; builds with practice; can decline with illness or environment
- Specific decision at a specific point in time
- Independence is not required. (Can use support similar to a translator or cultural broker)
- It is ok to influence or delegate decisions
- Watch for coercion



# Getting Started

- No pre-requisites
- Everyone communicates and everyone has a perspective
- Often people have capacity and capacity is overlooked
- Sometimes people don't have capacity...yet
- People who don't have capacity can often provide information
- A Supported Health-Care Decision-Making Agreement is an authorization, not a contract—minimal capacity needed



# Learning How to Listen

- Presume competence
- Facilitate communication access (relevant vocabulary including “no” and “I’m being mistreated”)
- Be patient
- Be clear about when you are translating and when guessing
- When decisions are substituted, base them on best understanding of will and preference rather than best interest standard
- Your best is good enough



# Learning How to Decide

- Attend all meetings
- Build a circle of people you trust
- Decide, even if it is scary
- Take some risks
- Learn to say “no” and “I am being mistreated”
- Set clear boundaries with supporters





# Common Support Problems

- Excluding clients from meetings
- Talking over clients
- Not preparing clients
- Not offering all options
- Confusing resistance or non-cooperation with refusal
- Substituting your own values and preferences
- Dehumanization
- Assuming that decisions never change
- Failing to provide communication support
- Assuming that because someone couldn't decide in the past, they can't decide now



# How to Avoid or Call Out Coercion

- Suspect someone is substituting a decision
  - Ask “How do you know?” and “Did you ask?”
- Suspect someone acting on competing interest
  - Distinguish each person’s interests by making a chart of what is important to/for
- Environmental problems
  - Preparation
  - Structure and ground rules for meeting
  - Attend to sensory environment
  - Attend to anxiety
  - Follow up
- If someone has had a lot of compliance training, teach skills for setting boundaries and respect them



# Goals of Care Conversations

- Your life is meaningful and valuable
- Coercion is common in conversations about end of life
- Complex disability is often confused with terminal illness
- Even if you aren't elderly or sick, it is important to have an advanced directive
- Advanced planning helps:
  - <http://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>



# Supporting Communication

When Listening is complicated:

Skills for honoring the individual perspectives of every person with disabilities

Ruti Regan: <http://www.ucsd.tv/search-details.aspx?showID=32191>

The Other Option

Dave Hingsburger: <http://davehingsburger.blogspot.ca/2016/12/the-other-option.html>

What's Next? A Self-Advocate's Guided Tour through Transition for Parents and Other Supporters

Melissa Crisp-Cooper:

[http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf\\_docs/FINAL%20Trans%20Guide%2011.18.16%20ALL\\_0.pdf](http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/FINAL%20Trans%20Guide%2011.18.16%20ALL_0.pdf)



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**Office of Developmental Primary Care**

Improving outcomes for people with developmental disabilities

# Supporting Communication

What I Wish My Doctor Knew About People who Accompany Us to OUR Medical Appointments

Melisa Crisp-Cooper:

[http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf\\_docs/WIW%20Attendants.pdf](http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/WIW%20Attendants.pdf)

What I Wish My Doctor Knew About Non-Traditional Communicators

Joel Smith:

[http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf\\_docs/wiw%20non%20trad%20communicators%20final\\_0.pdf](http://odpc.ucsf.edu/sites/odpc.ucsf.edu/files/pdf_docs/wiw%20non%20trad%20communicators%20final_0.pdf)

Supported Health Care Decision-Making

Office of Developmental Primary Care: <http://odpc.ucsf.edu/supported-health-care-decision-making>



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# Contact Information



Autistic Self Advocacy  
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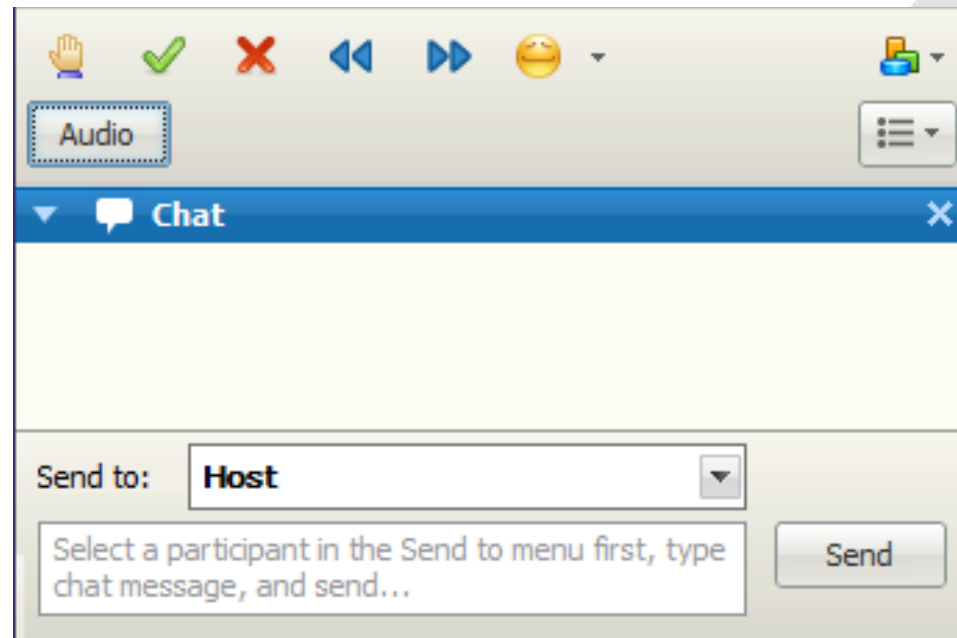


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# Questions?

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*Center for Future Planning*

## Next Webinar

# I/DD and Aging September 2017

If you have any questions, please contact us at  
[futureplanning@thearc.org](mailto:futureplanning@thearc.org)



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