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Evaluating Danger and Risk When Choosing to Use Supported Decision Making

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NGA “Position Statement on Guardianship, Surrogate Decision Making, and Supported Decision Making”

- “Under all circumstances, efforts should be made to encourage every person under guardianship: to exercise his/her individual rights retained and participate, to the maximum extent of the person's abilities, in all decisions that affect him or her, to act on his or her own behalf in all matters in which the person is able to do so, and to develop or regain his or her own capacity to the maximum extent possible.”

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Supported v. Shared v. Substituted



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When and How Much Should I Step In?

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Is the Person Lacking Capacity Or Is It Something Else?

- Is he in pain?
- Is he in a rush? Distracted?
- Are his emotions interfering?
- Are his hearing aids in?
- Can he read? In what language?
- What is his education level?
- Are there personal, cultural, economic factors?

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Watching Out For Red Flags

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Capacity vs. No Capacity

- Capacity for what?
 - To express preferences?
 - To see the dangers?
 - To understand the consequences?
- Can the person connect the dots?
- A person can be very verbal and charming but not be able to understand the dangers

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Living In Danger

How Much Risk Is Allowed?

For Someone With Capacity?

For Someone Without Capacity?

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Respecting the Decisions of the Person Who Has Capacity

- Autonomy – People, with capacity, have the right to determine the course of their lives
- **People have the right to make a wrong decision**
- Limit to this right – When our actions cause significant harm others: “The Harm Principle” by John Stuart Mills
- Is the help/advice you are offering wanted?
- How do you manage your frustration when the person is making a “foolish” decision?

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Our Obligations Change As the Person’s Capacity Changes

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My Denial About My Dad’s Falling



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But She is Okay Some of the Time!

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I Don't Want to Accept That Mom Needs Help!

- Do you know which days or times of day she will be fine?
- If there is a fire, will she be able to get out of the house and call for help, even on the days when she isn't doing well?
- I had the sisters repeat to themselves: *"We can't take a chance that the danger will happen on one of her bad days."*

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The Shared Decision Making Model

Approximate Developmental Age	Decision Making Tool	With adults, who participates?
Age 0-6	Decision Maker's Consent	The patient's decision maker uses Substituted Judgment or the Best Interest Standard.
Age 7-13	Assent	The decision maker, with the help of the doctor if needed, talks to the patient about the medical decisions and gets the patient's assent/dissent. The decision maker gives the final consent.
Age 14-17	Consent	If the patient has enough capacity, the patient uses autonomy and makes the decisions. If not, you move back up one level and use Assent.

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The Sliding Scale for Decision Making

How serious is this situation?
Is it safe for the person to participate?

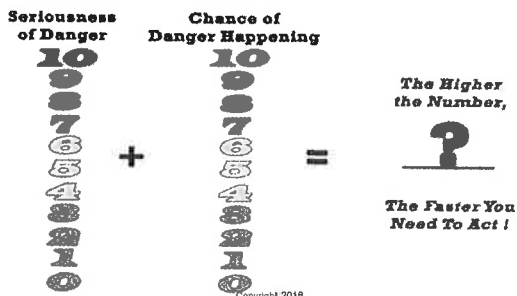
No capacity	A little bit of capacity	Some capacity	Almost full capacity	Full capacity
No decision making	Some small decisions	Daily decisions and some voice in medical decisions, but not life-and-death decisions	Larger voice in important decisions	Full voice in his or her own decisions, including life-and-death decisions

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Balancing the Seriousness with the Chance the Danger Will Happen

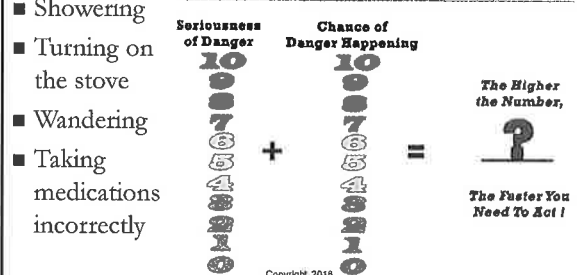
EVALUATING RISK FOR THOSE WITHOUT CAPACITY



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What is *this person's* score when he or she is *not thinking* clearly?

EVALUATING RISK FOR THOSE WITHOUT CAPACITY



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Short-Term Plan vs. Long-Term Plan

- **Lower Score:** Take some time to develop a good long-term plan which both protects the person and provides a good quality of life
- **Higher Score:** Take action quickly and put a short-term plan in place. Then take some time to create a better long-term plan
- Knew my dad was in danger, so I moved him immediately into a skilled nursing facility
- They placed in restraints to keep him “safe”

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Have I Really Made My Dad Safer or Are There New Dangers I Should Be Aware Of?

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Physical/Chemical Restraints Risks

- | | |
|---------------------------------------|--|
| ■ Falls | ■ Sleep disturbances |
| ■ Strangulation | ■ Fear, agitation, frustration |
| ■ Pressure Sores | ■ Loss of hope and internal motivation |
| ■ Decreased Mobility | ■ Loss of dignity and humiliation |
| ■ Loss of muscle tone and stiffness | ■ Increased boredom, loneliness and helplessness |
| ■ Reduced Bone Mass/Fractures | ■ Feelings of being punished |
| ■ Increasing weakness | ■ Depression, isolation, withdrawal |
| ■ Incontinence | ■ Thoughts of suicide |
| ■ Constipation/Impaction | ■ Learned dependence |
| ■ Infection | ■ Diminished staff opinion of resident |
| ■ Restricted breathing and aspiration | ■ Death |

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If I Could Go Back in Time, What Should I Have Done?

No One-Size-Fits-All Solution

—
Seek Least Restrictive Option

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How Do I Step In?

Creating a Plan That Keeps the Person Safe While Providing for a Good Quality of Life

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Balance Reducing the Risk While Improving Person's Quality of Life

- A life without danger may mean a life without meaning
- What are the **burdens** of the solution?
 - Emotional, physical, loss of control and dignity?
- What will it **feel like and be like** for the person to experience this decision?
- If the person loses a part of their quality of life, what can we add to put more quality back into their life?

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Can We Include and Empower The Person in the Solution?

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A Positive Approach To Evaluate the Person's Needs, Abilities and Situation



The Cards I've Been Dealt

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Steps to Asking for Assent/Dissent

- 1. Evaluate the person's mental age, maturity level, psychological condition and ability to give assent/dissent.
- 2. Allow enough time to use an alternate method of communication. You may need to slow down and repeat yourself a number of times.
- 3. Using developmentally appropriate language (language the patient can understand), give the person the necessary information about his or her illness. You may want to use pictures, a video or a simply written handout.

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Be Creative and Have Patience

- Take the time
 - Get to know the person
 - Help them learn about the options
 - Help them evaluate the choices
 - Repeat information again over time
- Communication – auditory, visual, kinesthetic
 - Videos, Pictures, Stories
- Practice
 - Role model
 - Do a trial run

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- 4. Give the person the details of the proposed treatment, test or surgery. Explain what the experience will be like *from the patient's perspective*.
 - What will it be like for the patient to experience the proposed treatment, test or surgery? Where will the test take place?
 - Will the test hurt? Will the patient be left alone or can you stay with your loved one during the procedure?
- 5. If the person says yes, be careful that the person isn't just saying that to make you happy.
- 6. If the patient doesn't understand what you are talking about, then try again. If the person still can't understand, then you shouldn't use assent.

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Let's Try Out Our New Skills

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Can the Person Make Her Own Financial Decisions?

What Level of Decision is Safe for THIS Person?

Would You Let the Person Carry \$5? \$20? \$100?

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Evaluating the Decision and How Much the Person Can Participate

- What kind of decision needs to be made?
- How much risk is involved?
- How hard would it be to undo the decision?
- Has the person made a decision like this before?
- Is the decision likely to be challenged?
- Ask: What is the least restrictive support?

Morgan K. Whitlatch, Legal Director, Quality Trust Lead Project Director, National Resource Center for Supported Decision-Making

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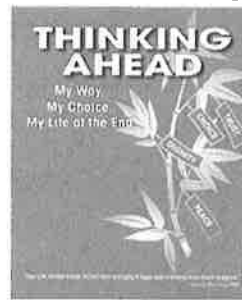
Using the Worksheet To Develop A Better Long-Term Plan

- Are there experts I can ask for advice?
- Will this option keep the person safe?
- Will it create any new risks?
- Can I include and empower the person in this decision?
- What will it feel like and be like for the person to live with this solution?
- What else can I do to improve this person's quality of life while keeping him/her safe?
- How much time do you have? Time to spend?

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Find Resources To Make It Easier "Thinking Ahead Project"



- Communicating About End of Life Workbook
- English, Spanish, Chinese
- Videos

www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm

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Gratitude

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- <https://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>
- Model Forms:
 - <http://supporteddecisionmaking.org/node/390>
 - <http://www.supporteddecisionmaking.org/node/390>
- Supported Decision-Making Guides:
 - <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- Archived Webinars:
 - <http://www.supporteddecisionmaking.org/education>

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