The Fine Art of Balancing Protection with Self Determination

David Godfrey, Senior Attorney at the American Bar Association

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

September 22, 2015



National Elder Rights Training Project for the National Legal Resource Center.

Sponsorship for this Webinar is provided by the National Consumer Law Center and a grant from the Administration for Community Living.

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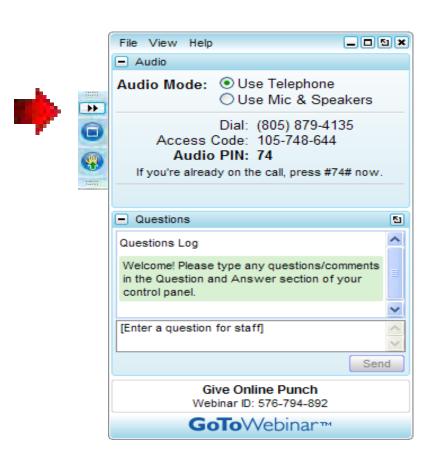
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National Legal Resource Center

- Partnership of five national organizations providing legal support to aging advocates
- Request technical assistance, case consultation and training
- Articles and information
- http://nlrc.acl.gov



- **Prevention Intervention Demonstration** Grants(08/10/2015)
- Elder Justice Coordinating Council's Report to Congress & PDF (08/10/2015)
- Blog on Age Discrimination in Employment @ (07/16/2015)
- Seniors & the Law A Guide for Maturing Californians (07/16/2015)



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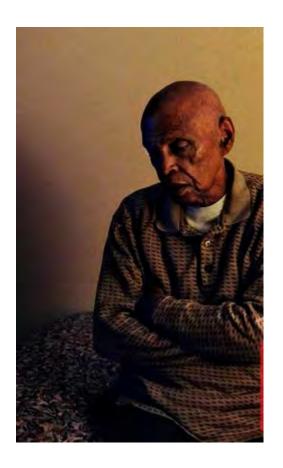
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- The Role of Long Term Care Ombudsman and Legal Aid Attorneys
- The Role of Adult Protective Services, Legal Aid, and Protection and Advocacy
- Representing Clients in Guardianship Actions: Winning the Case for Supported Decision Making
- Restoring Public Benefits Compromised by Elder Financial Exploitation
- Legal Remedies to Financial Exploitation: "Let's Get Grandpa's House Back!"
- Recovering Assets Lost to Financial Abuse: "Can I get their Money Back?"
- Transactional Capacity and Vulnerability to Elder Abuse

Our next webinar

- Representing Clients in Guardianship Actions: Winning the Case for Supported Decision Making
- October 20, 2015
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Presenter – David Godfrey

- David is a senior attorney to the ABA Commission on Law and Aging in Washington DC. He is responsible for the ABA's role in the Administration on Aging funded National Legal Resource Center and for producing the National Aging and Law Conference.
- He is a board member of the National Academy of Elder Law Attorneys.
- Prior to joining the Commission he was responsible for elder law programming at Access to Justice Foundation in Kentucky.
- David earned his B.A. with honors at Rollins College in Winter Park, Florida, and his J.D. cum laude from the University Of Louisville School Of Law in Kentucky.



Presenter – Jonathan Martinis

- Jonathan is the Legal Director of Quality Trust for Individuals with Disabilities and the Project Director of the National Resource Center for Supported Decision-Making.
- Jonathan has over twenty years' experience representing people with disabilities to protect their legal and human rights. In 2013, Jonathan represented Margaret "Jenny" Hatch in the "Justice for Jenny" case the first to hold that a person has the right to use Supported Decision-Making to make her own life choices instead of being subjected to a permanent, plenary guardianship.
- He has spoken to and trained thousands of people, families, attorneys, advocates, judges, teachers, health care workers, and other professionals across the country about everyone's Right to Make Choices and direct their own lives while receiving the services and supports they need to do so.

THE FINE ART OF BALANCING EMPOWERMENT AND PROTECTION

Jonathan Martinis David Godfrey

Supported Decision-Making: Protecting Rights, Ensuring Choices

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

THERE ARE STUPID QUESTIONS

What's Your Favorite Right?

RIGHTS=CHOICE

"I am my choices. I cannot not choose. If I do not choose, that is still a choice. If faced with inevitable circumstances, we still choose how we are in those circumstances."

- Jean Paul Sartre

RIGHTS=CHOICE CHOICE=SELF-DETERMINATION

- Life control
- People's ability and opportunity to be "causal agents . . . actors in their lives instead of being acted upon"

(Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440).

BENEFITS OF SELF-DETERMINATION

People with greater self determination are:

- Healthier
- More independent
- More well-adjusted
- Better able to recognize and resist abuse (Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998).

ANOTHER STUPID QUESTION

Are Your Rights Worth ANYTHING If You're Not Allowed to Use Them?

AND YET: 2,000 YEARS AND COUNTING

- Ancient Rome: "Curators" appointed for older adults and people with disabilities.
- 5th Century Visigothic Code: "people insane from infancy or in need from any age . . . cannot testify or enter into a contract"
- Feudal Britain: divided people with decision-making challenges into "idiots" and "lunatics" and appointed "committees" to make their decisions

GUARDIANSHIP IN THE US

- "Plenary" or "Full" Guardianship
- Gives the Guardian power to make ALL decisions for the person.
- Used in the VAST MAJORITY of cases
- "As long as the law permits plenary guardianship, courts will prefer to use it."

(Frolik, 1998)

As A RESULT

Guardians have "substantial and often complete authority over the lives of vulnerable [people]."
4 NAELA J. 1, 7 (2008).

This includes power to make the most basic health, personal, and financial decisions.

AARP, Guardianship Monitoring: A National Survey of Court Practices 1-2 (2006).

WE'VE KNOWN FOR FORTY YEARS

When denied self-determination, people:

- "[F]eel helpless, hopeless, and self-critical" (Deci, 1975, p. 208).
- Experience "low self-esteem, passivity, and feelings of inadequacy and incompetency," decreasing their ability to function (Winick, 1995, p. 21).

THE PROBLEM

"The typical ward has fewer rights than the typical convicted felon By appointing a guardian, the court entrusts to someone else the power to choose where they will live, what medical treatment they will get and, in rare cases, when they will die. It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen." (House Select Committee on Aging, H.R. Rpt. 100-641 (opening statement of Chairman Claude Pepper))

DINO AND LILLIAN

(credit: "To Collect Debts, Seizing Control Over Patients" New York Times, 1/25/15)



DINO AND LILLIAN

- Married over 45 years
- Worked together to develop Powers of Attorney and Advanced Directives
- When Lillian developed dementia, chose a nursing home for her

DINO AND LILLIAN

After Dino asked questions about a bill and Lillian's care

- Nursing Home petitioned for a plenary guardianship - giving ALL decision-making rights to a stranger
- Nursing Home's attorney: "[G]uardianship is a legitimate means to get the nursing home paid."

WHERE DO WE GO FROM HERE?

Guardianship MAY be Needed:

- In emergency situations when
 - The person is incapacitated and cannot give consent
 - The person did not previously identify how decisions should be made in that situation
 - There is no one else available in the person's life to provide consent through a Power of Attorney, Advanced Directive, or other means
- To support People:
 - Who face critical decisions and have no interest in or ability to make decisions
 - Who need immediate protection from exploitation or abuse

GUARDIANSHIP IS NEVER NEEDED

JUST

- "Because you're ____ years old"
- "Because you're sick"
- "Because you need help"
- "Because that's the way its always been"
- "For your own good"

BUT WE MEANT WELL

"Experience should teach us to be most on our guard to protect liberty when the Government's purposes are beneficent. . . . The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding." Olmstead v. U.S., 277 U.S. 438 (1928)

WE MUST'VE MEANT REALLY WELL...

Estimated number of adults under guardianship has **tripled** since 1995

(Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011).

RESEARCH

People under guardianship can experience a "significant negative impact on their physical and mental health, longevity, ability to function, and reports of subjective well-being" (Wright, 2010, p. 354)

ON THE OTHER HAND

 Older adults with more self-determination have improved psychological health including better adjustment to increased care needs.

(O'Connor & Vallerand, 1994)

People who exercise greater self-determination have a better quality of life, more independence, and more community integration.

(Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003)

AND

Women with intellectual disabilities exercising more self-determination are less likely to be abused (Khemka, Hickson, and Reynolds, 2005)

NEED MORE PROOF?

People with Intellectual and Developmental Disabilities who do **NOT** have a guardian are more likely to:

- Have a paid job
- Live independently
- Have friends other than staff or family
- Go on dates and socialize in the community
- Practice the Religion of their choice

2013-2014



So, Where DO We Go From Here?

If:

- We KNOW that some people need more support as they age or due to disability
- We KNOW that guardianship can result in decreased quality of life and
- We KNOW that increased self-determination leads to improved quality of life

Then we need a means of INCREASING self-determination while STILL providing support

A WAY FORWARD: SUPPORTED DECISION-MAKING

"a recognized alternative to guardianship through which people with disabilities 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).

THINK ABOUT IT

How do you make decisions?

What do you do if you're not familiar with the issue?

- ■Taxes?
- Medical Care?
- Auto Repairs?

So, Supported Decision-Making Is A Lot of Words For

Getting help when its needed

Just like you and me

So...

If a person can make decisions with assistance or support, is s/he incapacitated?

ARE YOU?

WHICH MEANS

Before seeking or recommending Guardianship:

What Else Have You Tried?

OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS

"Alternatives to guardianship, including supported decision making, should always be identified and considered whenever possible prior to the commencement of guardianship proceedings."

 National Guardianship Association Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making, 2015

SUPPORTED DECISION-MAKING CAN HELP PEOPLE

- Understand information, issues, and choices;
- Focus attention in decision-making;
- Weigh options;
- Ensure that decisions are based on their own preferences
- Interpret and/or communicate decisions to other parties.

(Salzman, 2011)

It's A Paradigm, Not A Process

There is no "one size fits all" method of Supported Decision-Making.

Can include, as appropriate

- Informal support
- Written agreements, like Powers of Attorney, identifying the support needed and who will give it
- Formal Micro-Boards and Circles of Support (Martinis, Blanck, and Gonzalez, 2015).

In Common

ALL Forms of Supported Decision-Making recognize:

- The person's Right to Make Choices on an equal basis with others;
- That a person can receive support in decisionmaking without giving up his or her Right to Make Choices; and
- People often need assistance in making or communicating their choices and there are many ways to provide that assistance
 (Dinerstein, 2012).

SUPPORTED DECISION-MAKING AND SELF DETERMINATION

"Supported Decision-Making has the potential to increase the selfdetermination 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)

THEREFORE

If you want the people you work with to be more independent, safer, and happier **EMPOWER** them to be more self-determined.

- NOTHING not Guardianship, not Supported Decision-Making is 100% "safe."
- BUT increased Self-Determination can increase safety

Abusers Target People

Who they perceive as being less likely to fight back



Why less likely

- Isolation
- Communication
- Credibility



Heightened Concerns

- Sometimes we hurt the ones we love
- Dependence on abuser



Signs and Signals -Abuse

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal



Signs and Signals - Exploitation

- Basic needs not being met
- Bills not being paid
- Living below means
- Things are missing
- Unexplained ATM or Credit Card
- Unexplained cash withdrawals
- Unexplained changes in lifestyle
- Retitling assets
- Changes in power of attorney



Signs and Signals – Caregiver Neglect

- Dependence on another
- Basic needs not being met
- Isolation
- Inappropriate living environment
- Caregiver not seeking resources or help
- Caregiver not assisting with needs
- Caregiver dismissive of wants and needs
- Changes in dress
- Changes in hygiene
- Changes in housekeeping
- Diet weight gain or loss
- Desire to see doctor not met
- Medications not available
- No social engagement
- Reading, entertainment
- Look around, smell, listen



Signs and Signals-Self Neglect

- Failure to meet basic needs despite ability
- Poor hygiene
- Lack of needed health care
- Unsafe living conditions



ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions









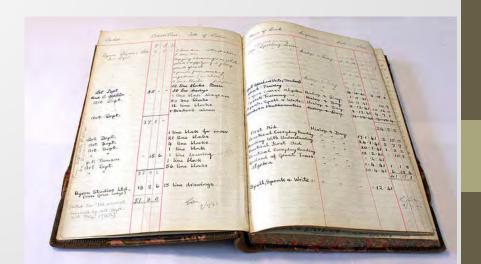
What are we looking for

- Understand options
- With support and guidance
- Makes a choice
- The standard is not
 - Best Interest
 - or
 - What's good for the person



Trust but Verify

- Draft accountings into powers of attorney
- Financial records to third parties (online access)
- Two signature accounts
- Limit Credit and ATM cards and monitor



Communication

- Offer choices
- Let the person make choices even if it is obvious they are making bad choices
- Communicate with all senses
- Even with very diminished capacity people will smile at what they prefer or grimace at what they don't



MONEY

- Discuss finances
- Have the person sign the checks as long as possible
- Ensure access to spending money
- Take them shopping
- Ask what they want, and do your best to honor it
- Control the stamps instead of the check-book?



MINIMIZE DANGER TO THE PERSON

Is the person likely to wander – GPS technology

Is the person confrontational? – Get the weapons out of

the house – have a safety plan

- Assure adequate
 - Nutrition
 - Clean place to live
 - Appropriate medical care
 - Appropriate clothing
 - · Safe home
- Secure valuables –
- Limit cash on hand
- Emphasize, not signing anything unless you are there
- Have back-up keys made
- · Be there



SERVICES TO EMPOWER

- Shopping and delivery services
- Home delivered meals, congregate meals
- Home health assistance
- Housekeeping assistance
- Friendly visitors callers
- Bill paying and financial management assistance
- Visiting pet services pet care assistance
- Handyman services
- Errand services
- Volunteer transportation



Supported Decision-Making: From Theory To Practice

Martinis
Legal Director,
Quality Trust for
Individuals with
Disabilities
Project Director,
National
Resource Center
for Supported

Decision-Making

Jonathan

NEVER FORGET

People with greater self determination are:

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- More independent
- More well-adjusted
- Better able to recognize and resist abuse (Khemka, Hickson, & Reynolds, 2005; O'Connor & Vallerand, 1994; Wehmeyer & Schwartz, 1998).

AMERICANS WITH DISABILITIES ACT

States must "administer [their] services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 CFR 35.130(d)

The "most integrated setting" is one "that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. Pt. 35, App. A (2010) (addressing 28 C.F.R. § 35.130).

OLMSTEAD

"[u]njustified institutional isolation . . . is a form of discrimination." *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 600-01 (1999)

Overbroad or undue guardianship "constructively isolate[s]" people from their communities (Salzman, 2010)

SUPPORTED DECISION-MAKING IS NOT NEW

In re Peery, 727 A.2d 539, 540 (Pa. 1999).
Guardianship terminated because person
"has in place a circle of support to assist her in making rational decisions concerning her personal finances and to meet essential requirements of health and safety."

MORE CASE LAW

Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct. Aug. 2, 2013), available at http://jennyhatchjusticeproject.org/docs/justicefor jenny trial/

Permanent guardianship denied. Friends
Jenny chose will "assist [Ms. Hatch] in
making and implementing decisions we have
heard termed 'supported decision making'"

LEGISLATION

H.B. 39 (Tx. 2015)

- Recognize Supported Decision-Making as a less-restrictive alternative to guardianship;
- Requires that Courts find that lessrestrictive alternatives are not feasible before imposing a guardianship;
- Authorizes Supported Decision-Making agreements

FEDERAL POLICY

Administration for Community Living Grant 90DM0001:

- Created "a national training and technical assistance center on . . . supported decision making."
- Supported Decision-Making is "an alternative to and an evolution from guardianship"

It's Already Required

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

Medicaid Waiver Services MUST:

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

It's ALREADY REQUIRED

Comment to ABA Model Rule 1.14 Regarding Clients with Disabilities

"The client may wish to have family members or other persons participate in discussions with the lawyer. When necessary to assist in the representation, the presence of such persons generally does not affect the applicability of the attorney-client evidentiary privilege. Nevertheless, the lawyer must keep the client's interests foremost and, except for protective action authorized under paragraph (b), must look to the client, and not family members, to make decisions on the client's behalf."

OPPORTUNITIES ARE ALL AROUND US

- "Informed Consent" to medical care
- "Person Centered Planning" in Medicare/Medicaid
- "The Conversation" and "Five Wishes" for End of Life Planning
- "Student Led" IEPs
- "Informed Choice" in Vocational Rehabilitation

START EARLY

Learn About the Person

- Who is, was, or can be in the person's life?
- What are the person's interests?
- Abilities, likes, dislikes, wants, needs?

Include this information in the person's Plan of Care and Records

APPLY WHAT YOU LEARN

Guiding Principals:

- MAXIMUM Self-Determination is Best
- **EVERYONE** Has the Right to Make Choices
- EVERYONE needs help making choices
- **EVERYONE** is an individual with individual abilities, limitations, wants, and needs

EXAMPLE: PRACTICAL DRAFT BY AMERICAN BAR ASSOCIATION

PRESUME that guardianship is not needed.

Reasons for concern – "What's the problem?"

Ask if the problem is temporary or easily addressable- "What's the root cause?"

COMMUNITY Connect with resources – "What would it take to solve the problem?" and "Who can provide that?"

TEAM Has the person already identified people s/he wants to work with?

DENTIFY If the person does not have a team, examine abilities, limitations, wants, needs, and contacts to see if a team can be made or supports provided

CHALLENGES Are there potential problems with team members or resources?

APPOINT If the person wants to give someone else the power to support or make decisions, help the person do it consistent with his or her wishes

LIMIT As a last resort, seek a guardianship limited to ONLY those areas the person cannot make decisions with or without support

EXAMPLE: VOLUNTARILY ASSIGNING DECISION-MAKING AUTHORITY

"It is my and my agent's intent that we will work together to implement this [Power of Attorney/Advanced Directive/Agreement/Plan]. That means that I should retain as much control over my life and make my own decisions, with my agents support, to the maximum of my abilities. I am giving my agent the power to make certain decisions on my behalf, but my agent agrees to give primary consideration to my express wishes in the way she makes those decisions."

EXAMPLE: VOLUNTARILY ASSIGNING MEDICAL DECISION-MAKING

"My agent will only have "full power" to make health care decisions for me if I am unable to make decisions, either because the doctor in charge of my care (attending physician) decides that I lost this ability temporarily or my attending physician and a consulting doctor agree that I have lost this ability permanently.

Otherwise, 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."

FINANCIAL DECISION-MAKING

"I will not buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than \$X without my agent's agreement. For example, if I want to buy or sell a car for \$20,000, I would need my agent to agree or the sale could not go through.

In making decisions whether or not to buy, sell, manage, or otherwise take or exercise any interest in any tangible property or item costing or worth more than \$X, my agent and I will discuss the situation and give consideration to my express wishes before my agent decides whether or not to agree."

BANKING

"I agree that my agent will be listed as a joint account holder on all bank or other financial institution accounts — including checking and savings accounts, as well as credit and debit cards — that I have or open while this power of attorney is in effect.

I agree that I will not withdraw more than \$100 from any account, write a check for more than \$100, or otherwise cause more than \$100 to be withdrawn from or charged to any account unless my agent agrees.

I also agree that my agent will have access to records of any accounts I have with any banks or other financial institutions."

"GROWTH CLAUSE"

"My agent and I will review this [Power of Attorney/Plan/Advanced Directive/Agreement] to see if it should be changed or cancelled at least every [Months/Years]. However, unless my agent and I change the [], I cancel it, my agent resigns, or either I or my agent dies, it will continue."

NEVER FORGET: DINO AND LILLIAN

Supported Decision-Making
ONLY works if people respect
EVERYONE'S

Right to Make Choices.

REMEMBER THE CHALLENGE

EVERY great advance fundamentally changes the way "things have always been"

REMEMBER THE OBSTACLES

Change is HARD

"We were not promised ease. The purpose of life . . . is not ease. It is to choose, and to act upon the choice. In that task, we are not measured by outcomes. We are measured only by daring and effort and resolve."

Stephen R. Donaldson

REMEMBER THE GOAL

EVERY person the "causal agent" in **EVERY** decision in his or her life.

- We all need help making decisions
- Older adults may need more or different help but have the SAME rights

JOIN THE CONVERSATION

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

Jonathan Martinis, Legal Director JMartinis@DCQualityTrust.Org

About this Project

This project was supported, in part by grant number 90DM0001 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

www.americanbar.org/aging

National Aging and Law Conference



National Aging and Law Conference



National Aging and Law Conference

On October 29-30, 2015, the Commission on Law and Aging and the Center for Professional Development will sponsor the National Aging and Law Conference in the Washington, DC, area.

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Next Series of Webinars



- Tune in for our next webinar in this series: October 20, 2015
Registration to come!

- Email us your ideas for speakers and topics to trainings@nclc.org

Just a Reminder

- Please fill out the evaluation when you sign-out
- The PowerPoint and recording will be emailed shortly
 - Thank you to our speakers!



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