

# Supported Decision- Making: Protecting Rights, Ensuring Choices

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**THERE ARE STUPID QUESTIONS**

What's Your Favorite  
Right?

# RIGHTS=CHOICES

“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=CHOICES

## CHOICES=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

# 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.
- **5<sup>th</sup> 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 U.S.

## “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



# GUARDIANSHIP IN DELAWARE

“The guardian of the person may exercise the same powers, rights and duties respecting the care, maintenance and treatment of the person with a disability that a parent has respecting the parent's own unemancipated minor child”

Delaware Code, Title 12, Section 3922

# 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).*

# WHEN PEOPLE ARE DENIED LIFE CONTROL

Study after Study shows:

- “[F]eel helpless, hopeless, and self-critical”  
- Deci, 1975
- Experience “low self-esteem, passivity, and feelings of inadequacy and incompetency,”  
decreasing their ability to function  
- Winick, 1995

# 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)

# 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 have \_\_\_\_”
- “Because you’re \_\_\_ years old”
- “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

# ON THE OTHER HAND

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

- Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & 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

# AND

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

# MARGARET “JENNY” HATCH

Margaret “Jenny” Hatch

Twenty-Nine year old woman with Down syndrome.

- High School graduate
- Lived independently
- Employed for 5 years
- Politically active



# THE SITUATION: FEBRUARY 2013

- Court Order putting Jenny in a “temporary guardianship”
- Living in a segregated group home
- No cell phone or computer, Facebook password changed
- Guardians controlled all access to her
- Working up to 5 days a week for 8 months  
– made less than \$1000

# Jenny's Rights In One Sentence

Guardians had the power:

“[T]o make decisions regarding visitation of individuals with Respondent, Respondent's support, care, health, safety, habilitation, education, therapeutic treatment and, if not inconsistent with an order of commitment, residence.”



# WHY?

## FROM THEIR EXPERT

On Jenny's:

- Independent Living Skills: **“If she had assistance, she may be able to do that”**
- Legal Skills: **“she would need assistance to understand a legal document”**
- Money Management: **She needs “assistance with [a] bank account.”**

## THEREFORE...

“She’s going to need assistance to make decisions regarding her healthcare, her living arrangements and such like that, she will need someone to guide her and give her assistance.”

AND...

“I believe what would be beneficial to Jenny is that she is afforded the opportunity to have individuals around her who support and love her, who give her the assistance she needs.”

# PETITIONERS' SWORN STATEMENT

How could Jenny execute a Power of Attorney?

“[N]ot only did Jenny have an opportunity to review the documents, but also the attorney had the opportunity to get to know Jenny and understand her capabilities and limitations in understanding legal documents. Based on this series of observations over several visits, the attorney concluded, and we concurred, that Jenny was capable of understanding these documents.”

# WHAT THAT ALL ADDS UP TO

Jenny Needs Support:

- To Understand Legal Issues
- To Understand Medical Issues
- To Understand Monetary Issues
  - In her Day to Day Life

**IN OTHER WORDS**

**JENNY IS A PERSON**

We Are All Jenny Hatch

# 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?

## What Do You Do?



**SO, SUPPORTED DECISION-MAKING IS A  
LOT OF WORDS FOR**

Getting help when its needed

**Just like you and me**

# AND JUST LIKE YOU AND ME:

Decisions Jenny had made with Support

- **Sign Power of Attorney**
  - **Consent to Surgery**
- **Medicaid Waiver Individual Service Plan**
  - **Application for Paratransit**
- **Authorization to share medical records**
- **Assignment of a Representative Payee**

# FINAL ORDER

- First 4 pages justify guardianship.

## **“However”**

- Guardians to be who she wants
- She lives where she wants
- Guardianship for only 1 year – Expired August, 2014
- Only over 2 things – medical and safety

# FINAL ORDER

**EVEN DURING** the 1 year limited guardianship:

**“Guardians shall assist Respondent in making and implementing decisions we have termed ‘supported decision making.’”**

# JENNY GOT JUSTICE



Jenny Hatch and her attorney celebrate after the court victory. (TWP)

## **‘I’m so happy to go home today’**

Theresa Vargas

Jenny Hatch, a 29-year-old-woman with Down syndrome, can live the life she wants after a judge rules she can reside with friends.

# WHY?

**Jenny is Strong, Smart, Determined  
AND**

She had support from:

- Friends and professionals
- National Organizations and Leaders
- Media
- A Judge who was willing to Listen and Learn

**IN OTHER WORDS**

**Jenny Got Lucky**

# THE LESSON JENNY TEACHES US

Justice and Self-Determination should:

- **NEVER** depend on luck or who you know.
- **ALWAYS** Be the Rule **NOT** the Exception



# So, WHERE DO GO FROM HERE?

## When Should a Person Be Put Under Guardianship?

The Court of Chancery shall have the power to appoint guardians for the person or property, or both, of any person with a disability . . . who

By reason of mental or physical incapacity is **unable properly to manage or care for their own person or property, or both**, and, in consequence thereof, is in danger of dissipating or losing such property or of becoming the victim of designing persons or, in the case where a guardian of the person is sought, such person is in danger of substantially endangering person's own health, or of becoming subject to abuse by other persons or of becoming the victim of designing persons

# THINK ABOUT IT

## WHAT DOES IT REALLY MEAN TO BE “UNABLE”

- People may be able “able” to make some decisions but not others.
  - Or be able to “manage or care for their person” only with assistance.
  - Or be unable to “manage or care for their property” unless they get help understanding the issues (legal, financial, etc) they face
- e.g. Salzman, 2010

**Capacity to take medication is not the same as capacity to prescribe it!**

So...

If people can only “manage or care” for their person or property **with assistance or support**, are they “unable”?

**ARE YOU?**

# WHICH MEANS: ASK A QUESTION

**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 BE “ABLE” TO MANAGE THEIR PERSON AND PROPERTY

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:

- That **EVERYONE** has the Right to Make Choices to the Maximum of Their Ability;
  - That you can get help exercising your Right to Make Choices without giving it up; and
  - That there are as many ways to give and get help as there are people
- Dinerstein, 2012.



# SUPPORTED DECISION-MAKING AND SELF DETERMINATION

“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

# PRECEDENT

- *In re Peery*, 727 A.2d 539 (Pa. 1999).
- *In re Dameris L.*, 956 N.Y.S.2d 848 (N.Y. Sur. Ct. 2012).
- *Ross v. Hatch*, No. CWF120000426P-03 (Va. Cir. Ct., 2013)
- *In re: Ryan Herbert King*, Case No. 2003 INT 249 (DC Sp Ct (Probate), 2016).
- *In re: CB*, Docket No. 4-9-16 OsGS, Sp Ct (Family Division)
- *In re: DD*, File No. 2014-2185, Surrogate's Court (Kings)

# ATTORNEYS: YOU'RE ALREADY DOING IT – OR SHOULD BE

Rule 1.14. Client with diminished capacity  
(a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

# RULE 1.14, COMMENT 1

“The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. . . . [A] client with diminished capacity often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being.”

## RULE 1.14, COMMENT 3

“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.”

# RULE 1.14, COMMENT 5

“If a lawyer reasonably believes that a client is at risk of substantial physical, financial or other harm unless action is taken . . . the lawyer [may] take protective measures deemed necessary. . . . **In taking any protective action, the lawyer should be guided by such factors as the wishes and values of the client to the extent known, the client's best interests and the goals of intruding into the client's decisionmaking autonomy to the least extent feasible, maximizing client capacities and respecting the client's family and social connections.**”

# DELAWARE LAW ENDORSES IT

## Title 16, Chapter 94A

- (a) The purpose of this chapter is to do all of the following:
- (1) Provide assistance in gathering and assessing information, making informed decisions, and communicating decisions to adults who do not need a guardian or other substitute decision maker for such activities, but who would benefit from decision-making assistance.
- (2) Give supporters legal status to be with the adult and participate in discussions with others when the adult is making decisions or attempting to obtain information.
- (3) Enable supporters to assist in making and communicating decisions for the adult but not substitute as the decision maker for that adult.

## What Else Have You Tried?

# AFTER GUARDIANSHIP

“ In exercising these powers the Court shall substitute its judgment for that of the person with a disability to order relief from the incapacity or incapacities which the Court has found. In substituting its judgment, the Court shall act toward the property of the person with a disability as it believes to be **in the best interest of the person with a disability** and the estate of the person with a disability.”

Delaware Code, Title 12, Section 3901

## KEEP TRYING



# MAXIMIZING SELF DETERMINATION IS A PERSON'S "BEST INTERESTS"

Remember:

People with greater self determination are:

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

## KEEP TRYING!

# WHEN WHAT YOU TRIED WORKS!

“The Court of Chancery may remove a guardian for any sufficient cause.”

Delaware Code, Title 12, Section 3908

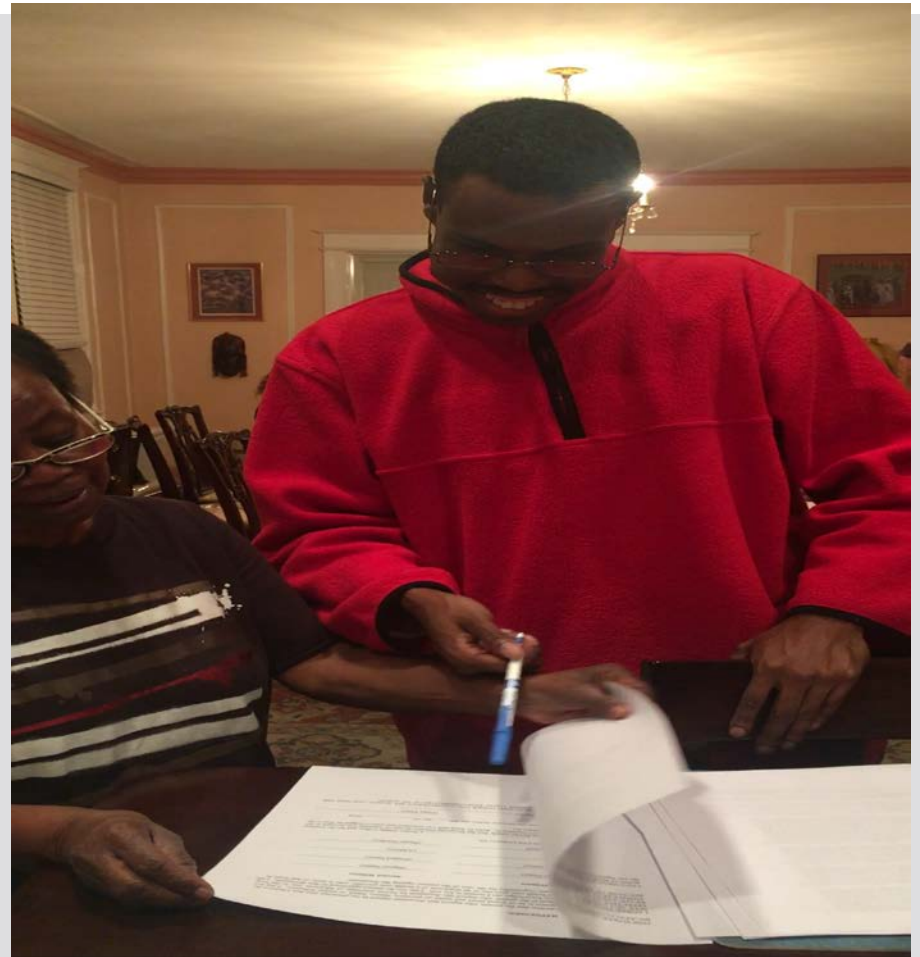
# DOESN'T THAT MEAN...

A Guardian's job is to work with the person:

- To help the person learn to make his or her own decisions, with support
- To build self-determination
- To learn to “manage” his or her person and property
- And then ask the Court to terminate the guardianship?

**Guardianship as a Way-Station, Not a Final Destination**

# IT CAN HAPPEN



# THE ELEPHANT IN THE ROOM: SAFETY

**NOTHING:** Not Guardianship, Not Supported Decision-Making is 100% "Safe."

**HOWEVER:** Supported Decision-Making Increases Self-Determination (Blanck & Martinis, 2015), which is correlated with increased Safety (Khemka, Hickson, & Reynolds, 2005).

# SIGNS AND SIGNALS –ABUSE, NEGLECT, EXPLOITATION

- Injuries
- Unusual bruising or abrasions
- Fear or nervousness
- Withdrawal Basic needs not being met
- Bills not being paid
- Living below means
- Unexplained changes in lifestyle

# REMEMBER: PROTECTION IS AVAILABLE

If you see Abuse, Neglect or Exploitation:

Neglect

- Police
- APS
- CPS
- Attorney General's Fraud Unit
- Protection and Advocacy System

# BUT REMEMBER: ADULTS ARE ALLOWED TO MAKE BAD DECISIONS

- Health
- Money
- Love
- Living Conditions



# REMEMBER!

Supported Decision-Making  
ONLY works if we Recognize,  
Respect, and Honor  
EVERYONE's Right to Make  
Choices

# OPPORTUNITIES FOR SDM ARE ALL AROUND US

- **Education:** “Student Led” IEPs
- **Employment:** “Informed Choice” in Vocational Rehabilitation
- **Medical Care:** Person Centered Planning for Medicaid and Waivers
- **Adult Services:** Centers for Independent Living PASS plans, ABLE Accounts

# REMEMBER THE CHALLENGE

**EVERY** great advance in civil rights fundamentally changed 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

# CHANGE THE CULTURE, CHANGE THE WORLD!

“Long after the schools, Vocational Rehabilitation, early interventionist, behavioral consultants, and para-educators have gone. the students will be adults. . . We [are] ethically, morally, and fiscally responsible for supporting their lives of success and meaning. . . . We have the tools, we have the means . . . we have the vision.”

Gustin, 2015

# JOIN THE CONVERSATION

**National Resource Center for Supported Decision-Making:**

**[SupportedDecisionMaking.Org](http://SupportedDecisionMaking.Org)**

**The Burton Blatt Institute at Syracuse University: [BBI.Syr.Edu](http://BBI.Syr.Edu)**

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