

# Developmental Disabilities Lecture Series

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## **Supported Decision-Making: Change the Culture, Change the World!**

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**Supported Decision-Making:  
From Justice for  
Jenny to Justice for  
All!**

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**THERE ARE STUPID QUESTIONS**

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**What's Your Favorite  
Right?**

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**RIGHTS=CHOICE**

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"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

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**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

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**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

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**ANOTHER STUPID QUESTION**

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

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### 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

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### 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
- Teaster, Wood, Lawrence, & Schmidt, 2007.
- “As long as the law permits plenary guardianship, **courts will prefer to use it.**”
- Frolik, 1998

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### 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).*

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### AS WE'VE KNOWN FOR FORTY YEARS

When denied self-determination, people:

- “[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

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### 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)

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### 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

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**GUARDIANSHIP IS NEVER NEEDED**

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**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”

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**BUT WE MEANT WELL**

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“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)

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**WE MUST’VE MEANT REALLY WELL**

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

- Reynolds, 2002; Schmidt, 1995; Uekert & Van Duizend, 2011

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**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

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**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, Rifenbark, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

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**AND**

Women with intellectual disabilities exercising more self-determination are **less likely to be abused**

- Khemka, Hickson, and Reynolds, 2005

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### 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 

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### 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

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### 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




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**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

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**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.”

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**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.”**

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**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.”

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**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.”

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**IF JENNY CAN’T MAKE DECISIONS. . .**

. . . How could she sign 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.”

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**WHAT THAT ALL ADDS UP TO**

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Jenny Needs Support:

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

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**IN OTHER WORDS**

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**JENNY IS A PERSON**

We Are All Jenny Hatch

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**A WAY FORWARD:  
SUPPORTED DECISION-MAKING**

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“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

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**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?**

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

Getting help when its needed

**Just like you and me**

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**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

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**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

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**FINAL ORDER**

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

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

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**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.

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**WHY?**

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**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

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**IN OTHER WORDS**

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**Jenny Got Lucky**

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**THE LESSON JENNY TEACHES US**

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Justice and Self-Determination should:

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

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**SO, WHERE DO GO FROM HERE?:  
WHEN IS GUARDIANSHIP NECESSARY?**

General Guardian. If the court finds that an individual is incapacitated as defined in N.J.S.3B:1-2 and is without capacity to govern himself or manage his affairs, the court may appoint a general guardian who shall exercise all rights and powers of the incapacitated person. .

Limited Guardian. If the court finds that an individual is incapacitated and lacks the capacity to do some, but not all, of the tasks necessary to care for himself, the court may appoint a limited guardian of the person, limited guardian of the estate, or limited guardian of both the person and estate. . . . A judgment of limited guardianship may specify the limitations upon the authority of the guardian or alternatively the areas of decision making retained by the person.  
**N.J.S 3B:12-24.1**

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**TWO THINGS NEEDED**

- **Incapacity as defined by NJ law**
- AND
- **Incapacity to “govern” themselves or “manage” their affairs**

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**WHAT DOES IT MEAN TO BE  
“INCAPACITATED”**

"Incapacitated individual" means an individual who is impaired by reason of mental illness or intellectual disability to the extent that the individual lacks sufficient capacity to govern himself and manage his affairs.

N.J.S.3B:1-2

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**THINK ABOUT "CAPACITY"**

- People may have "capacity" to make some decisions but not others.
  - Or be able to "manage" affairs some times but not others.
  - Or be unable to "govern" themselves unless they get help understanding the situations they face.
- E.g. Salzman, 2010  
**Capacity to take medicine is NOT the same as capacity to prescribe it**

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**So...**

If person - "incapacitated" or not – can only "govern" or "manage" when he or she has support, does that person lack capacity?

**DO YOU?**

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**WHICH MEANS: ASK A QUESTION**

Before seeking or recommending Guardianship:

**What Else Have You Tried?**

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**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

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**SUPPORTED DECISION-MAKING CAN ADDRESS LIMITATIONS IN DECISION-MAKING**

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

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**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

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**IN COMMON**

**ALL** Forms of Supported Decision-Making recognize:

- That EVERYONE has The Right to Make Choices to the maximum of their capabilities;
  - That people can get help exercising their Right to Make Choices without giving up that right; and
  - There are as many ways to give and get help as there are people
- e.g., Dinerstein, 2012

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**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

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**AND EVEN WHEN A PERSON IS IN A GUARDIANSHIP**

“In taking or forbearing from any action affecting the personal needs of a ward, a guardian shall give due regard to the preferences of the ward, if known to the guardian or otherwise ascertainable upon reasonable inquiry.”

**N.J.S. 3B:12-57**

**WHAT ARE YOU TRYING**

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**THE WHOLE POINT OF GUARDIANSHIP**

“In the exercise of the foregoing powers, the guardian shall encourage the ward to participate with the guardian in the decision-making process to the maximum extent of the ward's ability in order to encourage the ward to act on his own behalf whenever he is able to do so, and **to develop or regain higher capacity to make decisions in those areas in which he is in need of guardianship services, to the maximum extent possible.**”

NJS 3B:12-57

**KEEP TRYING!**

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**WHEN WHAT YOU TRIED WORKS**

“ The Superior Court may . . . adjudicate that the incapacitated person has returned to full or partial competency and restore to that person his civil rights and estate as it exists at the time of the return to competency if the court is satisfied that the person has recovered his sound reason and is fit to govern himself and manage his affairs”

NJS 3B:12-28

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**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 help the person learn to “govern” themselves and “manage” their affairs
- And then ask the Court to terminate the guardianship?

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

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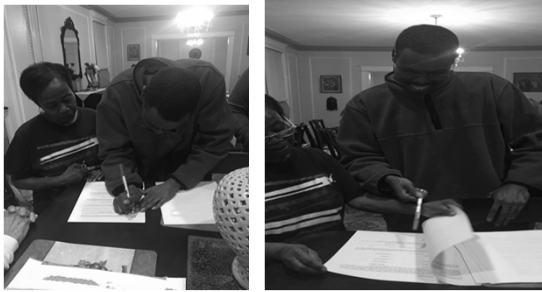
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**IT CAN HAPPEN**



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**It DOES HAPPEN**



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**BUT IT WILL ONLY HAPPEN  
IF WE REMEMBER**

Supported Decision-Making  
ONLY works if we recognize,  
respect, and protect  
**EVERYONE'S**  
Right to Make Choices.

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**AND**

Opportunities for Support Are All Around Us

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

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**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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**Supported Decision-Making  
From Theory to Practice:**

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**Article of Faith**

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Students who have self-determination skills are more likely to successfully make the transition to adulthood, including improved education, employment and independent living outcomes.  
- Wehmeyer & Schwartz, 1997

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**Getting There: The Individuals  
with Disabilities Education Act**

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“Under IDEA, schools must ensure that students in special education receive services reasonably calculated to enable the child to receive educational benefits.”  
*Board of Education v. Rowley*, 458 U.S. 176 (1982)

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### WHAT ARE EDUCATIONAL BENEFITS?

- Providing students with a Free Appropriate Public Education?
- Educating students in the Least Restrictive Environment?
- Helping students with disabilities access the general curriculum?
- Increasing inclusion?

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### These are Educational Benefits!

Purpose of the IDEA:

“to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and **prepare them for further education, employment, and independent living.**”

20 U.S.C. § 1400(d)(1)(A) (emphasis added).

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### Therefore

Self determination is the ultimate goal of education  
- Halloran, 1993

Promoting self-determination is a special educational “best practice”  
- Wehmeyer & Hughes, 1998

Schools should focus on improving students’ ability to set goals, solve problems, make decisions and advocate for themselves and, just as importantly, to give students the opportunity to exercise these skills.  
- Wehmeyer & Gragoudas, 2004

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**And Yet  
The “Default Option”**

- School personnel are the most frequent source of recommendations that parents seek guardianship/conservatorship - Jameson, et al, 2015
- School personnel recommending guardianship/conservatorship often don't discuss alternatives like SDM with parents – Jameson, et al., 2015

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**Shut Down the On Ramp**

- Effective Special Education Advocacy **MUST** focus on Self-Determination.
- If Self-Determination is the “Default Option” Guardianship isn't even a consideration!

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**Start Early**

- Self-Determination and Decision-Making should be written into IEPs **AS SOON AS POSSIBLE.**
- DC Public Schools includes it in pre-K!

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**DISTRICT OF COLUMBIA PUBLIC SCHOOLS**

- Teaches students as young as 3 to use SDM and “build networks of support . . . to ensure that they are familiar with the process and utilize it in day to day activities.” Sets an important precedent and pattern.
- Works with parents to help them “extend skills related to building supportive networks.”
- Parents can then help students understand “it is fine to advocate for supports and seek assistance if questions arise.”

- Downing-Hosten, P., 2015

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**Self-Determination:  
Make it a Goal**

IEP goals/objectives related to self-determination:

- For every goal, there should be an application of self-determination to get there.
- “I statements” in IEP goals and objectives to get student involvement and accountability

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**Examples: Behavior Goals**

- Instead of: "The Student will use proper grammar 75% of the time."

Try

- "I will work with my teacher to pick subjects I am interested in and write stories, using proper grammar in at least 3 out of every 4 stories."

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**SELF-DETERMINATION GOALS**

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■ Research shows that creating and implementing goals and supports focused on self-determination results in students becoming more self-determined and improving their performance in school and non-school activities. - Wehmeyer, M., Palmer, S., Shogren, K., Williams-Diehm, K., & Soukup, J, 2013

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**Creating and Reaching Those Goals:  
The Student Led IEP**

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**THE STUDENT** actually engages in self-determination

**THE STUDENT** can practice different decision-making methods in a “safe environment”

**THE STUDENT** leads meeting

**THE STUDENT** Identifies goals and objectives with assistance from professionals and people **THE STUDENT** invites

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**DOESN'T THAT SOUND LIKE**

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**SUPPORTED DECISION-MAKING**

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### THE STUDENT LED IEP IS CONSISTENT WITH RESEARCH

■ Students who led their IEP meetings “gained increased self-confidence and were able to advocate for themselves, interacted more positively with adults, assumed more responsibility for themselves, [and] were more aware of their limitations and the resources available to them.” - Mason, C. Y., McGahee-Kovac, M., & Johnson, L., 2004

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### Why Guardianship?

Guardianship happens when people can't “take care of themselves in a manner that society believes is appropriate.”

- Kapp, 1999

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### Learning to “Take Care” of Yourself: Transition Services

Transition services are “a coordinated set of activities”

- To “facilitate the child’s movement from school to post-school activities, including post-secondary **education**, vocational education, integrated **employment** (including supported employment), continuing and adult education, adult services, **independent living**, or community participation;”
- Are “based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and
- Include “instruction, related services, community experiences, the development of employment and other **post-school adult living objectives**, and, when appropriate, **acquisition of daily living skills** and functional vocational evaluation.”

20 USC 1401(34)

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**Transition Services**

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**Start:** "Beginning not later" than the year the student turns 16  
 - 20 U.S.C. § 1414(d)

**Continue:** At least until student is 21  
 - 34 CFR §300.101

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**YOU HAVE FIVE YEARS**

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- To "coordinate services"
- To "coordinate community experiences"
- To "coordinate the development of post-school adult living objectives"
- To "coordinate . . . the acquisition of daily living skills"
- To "prepare for further employment, education, and independent living"

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**Article of Faith**

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Wouldn't it be Great:  
 If there was a program that could help provide ALL the benefits of Self Determination and it was available to ALL people with disabilities?

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**COORDINATION OPPORTUNITY:  
VOCATIONAL REHABILITATION (VR)**

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VR program provides services and supports to help people with disabilities:

“prepare for, secure, retain, advance in, or regain employment”

Rehabilitation Act, 2006, § 722 (a)(1)

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**WELL, THEN...**

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If you need something/ANYTHING to prepare for work, get a job, or keep a job, you can get it through the VR program

INCLUDING decision-making and self-determination skills!

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**WHAT IF...**

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The skills you need to work are the **SAME** ones you need to build self-determination and avoid guardianship?

- Self-care
- Organization
- Communication
- Interpersonal Skills

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**EMPLOYMENT BASED SKILLS?**

Would **YOU** hire or retain someone who has difficulty:

- Following directions or staying on task?
  - Communicating with you or your customers?
  - Getting along with co-workers?

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**THEREFORE**

If these “life skills” limitations are related to a person’s disability and make it harder for him or her to prepare for, get, or keep work:

**VR MUST PROVIDE SERVICES AND SUPPORTS TO HELP OVERCOME THEM**

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**ELIGIBILITY FOR VR**

Your are eligible for VR if you

- Have a disability
- Want to Work

AND

- VR services will help you work.

If you receive SSI/SSDI you are **presumed eligible!**  
34 CFR 361.42

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**IT'S HARD TO BE INELIGIBLE**

If you have a disability, the VR agency must **presume you want to work.**

Before the VR agency can say that you are "too disabled" to work, they have to **give you a chance to work!**

You don't have to prove you can work, **they have to prove you can't!**

34 CFR 361.42

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**PLAN TO SUCCEED**

The Individualized Plan for Employment (IPE)

Lays out your employment goal – the job you want to get and the supports you need to get it

34 CFR 361.46

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**NOT JUST ANY JOB**

VR services are designed to help you get a job that fits **YOUR** skills and interests and **YOUR** choice!

34 CFR 361.46

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### VR CAN COVER A LOT

Some services that are available:

- Assessments
- Counseling
- Job search and retention services
- Assistive technology
- Medical and mental health care
- Education Expenses (including College)
- On the job training
- Job coaches
- Transportation
- "Maintenance" payments
- Interpreters
- Services to family members (like Day Care!)

34 CFR 361.48

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### SUPPORT IS BUILT-IN

VR Agencies must ensure that the person can exercise "informed choice"

**"Informing each applicant and eligible individual . . . through appropriate modes of communication, about the availability of and opportunities to exercise informed choice, including the availability of support services for individuals with cognitive or other disabilities who require assistance in exercising informed choice throughout the vocational rehabilitation process"**

- 34 C.F.R. 361.52

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### DOESN'T THAT...

Sound like Supported Decision-Making?

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**THAT MEANS  
VR CAN HELP PEOPLE:**

- Gain the skills needed to become employed **AND**
- The skills needed to demonstrate the ability to “take care of themselves in a manner that society believes is appropriate” and avoid guardianship or be restored from guardianship

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**ARTICLE OF FAITH**

“[P]hysical or mental disabilities in no way diminish a person's right to fully participate in all aspects of society”

The Americans with Disabilities Act,  
42 U.S.C. 12101

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**AND YET**

People with Disabilities have more medical conditions, yet are more often poorly diagnosed [and] over/under treated

- Office of the Surgeon General "The surgeon general's call to action to improve the health and wellness of persons with disabilities." (2005)

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**MAYBE THAT'S BECAUSE...**

In a recent survey, 10% of people under guardianship or who sought guardianship for someone identified a medical professional as the person who first recommended it.

- Jameson, et al 2015

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**THE SITUATION OUT THERE**

- In DC...
  - 70% of people served by Department on Disability Services have a guardian or substitute decision-maker.
  
- Nationally...
  - According to the CQL database, only one-half or fewer of the over 8,100 people reviewed were exercising choices about home, work, goals or services in a way that was meaningful to them.

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**KEY CONCEPT: "INFORMED CONSENT"**

- The Heart of the Dr/Patient relationship
  - Three Key Parts:
    - Information from Dr to person
    - Understanding by the person
    - Choice by the person and communication to Dr
- American Medical Association

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**AS WITH EVERY DECISION**

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- Assistance can be provided to help individual make medical decisions:  
     "Explain that to me in English"
  
- Ability to make decisions is a continuum. A person may be able to make some but not others  
     **Capacity to Consent to Surgery is NOT the Same as Capacity to Perform Surgery**

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**THEREFORE**

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There is a need to empower and enable Informed Consent in ways that are

- Flexible
- Immediate
- Improve Dr-Patient communication and collaboration
- Increase the role of family, friends, and people close to the patient

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**DOESN'T THAT SOUND LIKE SUPPORTED DECISION-MAKING?**

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People working with friends, family members, and professionals to help them understand the situations and choices they face so they can make their own decisions  
 - Blanck & Martinis, 2015

**"The solutions also are different for each person.** Some people need one-on-one support and discussion about the issue at hand. For others, a team approach works best. Some people may benefit from situations being explained pictorially. With Supported decision-making the possibilities are endless."  
 - Administration for Community Living, "Preserving the Right to Self-determination: Supported Decision-Making"

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**FORMS**

- Easy as adding language “and for decision-making purposes” in HIPAA release
- Or make up your own form.
- Or use models, like those found at [www.SupportedDecisionMaking.Org](http://www.SupportedDecisionMaking.Org)

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**CREATE AN AUTHORIZATION**

“I authorize [person’s name] to work with me to help me understand, make, and communicate my own medical decisions.

I intend for [person] to be treated as I would be with respect to my rights regarding the use and disclosure of my individually identifiable health information or other medical records. This release authority applies to any information governed by the Health Insurance Portability and Accountability Act of 1996 (aka HIPAA), 42 USC 1320d and 45 CFR 160-164 XII, and to other applicable federal and state laws regarding my medical care and records. ”

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**POA WITH SUPPORTED DECISION-MAKING**

Power of Attorney giving agent decision-making authority:

“It is my and my agent’s intent that we will work together to implement this Power of Attorney. 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.**”

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### MEDICAL POA

“If I am found to be incapable of making my own health care decisions as described above, my attorney-in-fact shall make decisions and take actions on my behalf as directed below or (if not directed below) in accordance with preferences I made known to her prior to my incapacity. If I had not previously made my preferences known, then, in making any decisions or taking any actions under the terms of this instrument, my attorney-in-fact will first discuss the situation and the decision to be made/action to be taken with me and give primary consideration to my express wishes before making the decision or taking action. If I am not capable of discussing the situation with my attorney-in-fact and I have not previously made my preferences known, my attorney-in-fact must use her best judgement to make the decision I would have made/take the action I would have taken in that situation, even if it is different from what she would have done in that situation.”

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### MEDICAL ADVANCED DIRECTIVE WITH SUPPORTED DECISION-MAKING

“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.”

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### “PERSON CENTERED PLANNING”

Person Centered Plan MUST:

- Address “health and long-term services and support needs in a manner that reflects individual preferences and goals.”
- Result “in a person-centered plan with individually identified goals and preferences, including those related community participation, employment, income and savings, health care and wellness, education and others.”
- <https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf>

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**PERSON CENTERED PLANNING FOCUSES ON**

What is:

- Important TO the Person
- Important FOR the Person

Where the Person is and where the Person wants to be

- What needs to change and what needs to stay the same to get there

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**DOESN'T THAT SOUND LIKE...**

**Supported Decision-Making?**

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**PLANNING THROUGHOUT THE LIFE COURSE**

Supported Decision-Making can work in a number of contexts – if it requires a decisions, Supported Decision-Making can help the person exercise the Right to Make Choices

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**EXAMPLE: FINANCIAL AUTHORITY**

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.**

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**EXAMPLE: 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 \$X from any account, write a check for more than \$X, or otherwise cause more than \$X to be withdrawn from or charged to any account unless my agent agrees.

In making decisions whether or not to agree to write checks, withdraw money from my accounts or charge money to my accounts, my agent and I will discuss the situation and **give consideration to my express wishes before my agent decides whether or not to agree.**

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**“GROWTH CLAUSE”**

“My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it **should be changed or cancelled at least every \_\_\_\_\_**. However, unless my agent and I change the power of attorney, I cancel it, my agent resigns, or either I or my agent dies, the [ ] will continue.”

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**EXAMPLE: END OF LIFE PLANNING**

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“The Conversation” and “Five Wishes”

A facilitated process where the Person makes decisions about hospice, palliative care, and services.

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**THE ELEPHANT IN THE ROOM: SAFETY**

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**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).

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**REMEMBER THE GOAL**

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**EVERY** person with self-determination, the “causal agent” in his or her life.

- We all need help making decisions
- Older adults and People with Disabilities may need more or different help but have the **SAME** rights

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**REMEMBER THE CHALLENGE**

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**EVERY** great advance in civil rights fundamentally changed the way “things have always been”

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**REMEMBER THE OBSTACLES**

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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

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**CHANGE THE CULTURE, CHANGE THE WORLD!**

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“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

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**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)

**Jonathan Martinis, Senior Director for Law and Policy:** [JGMartin@Law.Syr.Edu](mailto:JGMartin@Law.Syr.Edu)

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