

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

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FIRST PRINCIPALS

What's Your Favorite
Right?

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.

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: 1,500 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

- A Court holding that a person can't make some or all decisions and giving someone else the power to make the decisions the person can't.
- Most state laws, including NC, say that guardianship should be limited whenever possible – e.g. G.S. 35A-1201
- Nevertheless, the most common form of guardianship – used up to 90% of the time – is “full” or “plenary” where the guardian can make ALL decisions for the person.

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).

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.

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

- Older adults with more self-determination have improved psychological health including better adjustment to increased care needs.
 - O'Connor & Vallerand, 1994
- 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

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

2017-2018



NATIONAL
CORE
INDICATORS™

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 Have 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.”

HOW DID JENNY 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.”

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

WHERE DO WE GO FROM HERE?

WHY GUARDIANSHIP?

People may only be ordered into guardianship if they are “incompetent”

“An adult or emancipated minor who lacks sufficient capacity to manage the adult's own affairs or to make or communicate important decisions concerning the adult's person, family, or property” – GSA 35A-1101

AND

“the clerk determines that the nature and extent of the ward's capacity justifies ordering a limited guardianship” - GSA 35a-1212

WHERE DO WE GO FROM HERE?

THINK ABOUT “CAPACITY”

- People may have “capacity” to make some decisions but not others.
 - Or be able to make decisions about their property only with assistance.
 - Or only be able to make decisions regarding themselves and their property if they get help understanding them.
- e.g. Salzman, 2010

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

SO ASK A SMART QUESTION

If people can only “manage” their personal or financial decisions **with assistance or support**, are they “incapacitated?”

ARE YOU?

AND ASK ANOTHER

If people can make decisions when they have help, is guardianship “justified?”

SO ASK A REALLY SMART 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 “MANAGE” THEMSELVES AND THEIR 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

IT'S A COMMITMENT

ALL forms of Supported Decision-Making recognize:

- That **EVERYONE** has the Right to Make Choices to the maximum of their ability;
- That people can get help exercising their Right to Make Choices without giving it up; and
- There are as many ways to get help as there are people. Find the one that works for each person!

e.g., Dinerstein, 2010

MAKING IT HAPPEN

STEPS IN SUPPORTED DECISION-MAKING

Listen and Think

- Supported Decision-Making should always be based on the person's strengths, needs, and interests.
- Start by encouraging the person to think about life areas where he or she makes decisions now and those the person needs help to make.
- RESOURCE: When Do I Want Support:
<https://www.aclu.org/other/when-do-i-want-support>

MAKING IT HAPPEN

STEPS IN SUPPORTED DECISION-MAKING

Identify Opportunities and Challenges

- Explore the types of support the person wants to use.
- Talk about the support he or she uses now. If one way of supporting the person works well, think about trying it for other life areas.
- If you're not sure what to try, brainstorm about ways to give and get support
- RESOURCE: The "Supported Decision-Making Brainstorming Guide:"
<http://supporteddecisionmaking.org/sites/default/files/sdm-brainstorming-guide.pdf>

MAKING IT HAPPEN: STEPS IN SUPPORTED DECISION-MAKING

Find Supporters

- Connect with the people, professionals, agencies, and organizations that can provide the support the person wants.
- Consider support from programs like Medicaid Waiver, Centers for Independent Living, Aging and Disability Resource Center, DDS, DC Office on Aging.

MAKING IT HAPPEN

STEPS IN SUPPORTED DECISION-MAKING

Coordinate Support

- Work with the person, supporters, professionals, and agencies to develop a Supported Decision-Making plan laying out who will support the person and how the person will use that support.
- RESOURCE: “Setting the Wheels in Motion”:
<http://supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>

MAKING IT HAPPEN:

STEPS IN SUPPORTED DECISION-MAKING

Put it in Writing

- Create written plans saying who will give support, when, and how
- Incorporate SDM into Person Centered Plans
- Powers of Attorney or Advanced Directives with SDM
- Incorporate SDM into support plans for programs
- If person is in guardianship, incorporate SDM into guardianship reports

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

NC LAW RECOGNIZES THIS!

- Limiting the rights of an incompetent person by appointing a guardian for him should **not** be undertaken unless it is clear that a guardian will give the individual a **fuller capacity for exercising his rights.**
- Guardianship should seek to preserve for the incompetent person the opportunity to exercise those rights that are within his comprehension and judgment, allowing for the possibility of error to the same degree as is allowed to persons who are not incompetent. **To the maximum extent of his capabilities, an incompetent person should be permitted to participate as fully as possible in all decisions that will affect him.**

- G.S. 35A-1201

EVEN AFTER GUARDIANSHIP

Guardians must file reports each year detailing their efforts to:

- Help the person regain competency.
- Seek alternatives to guardianship for the person
- Implement a more limited guardianship “preserving for the ward the opportunity to exercise rights that are within the ward's comprehension and judgment”

G.S. § 35A-1242

WHEN IT WORKS

- The guardian, ward, or any other interested person may petition for restoration of the ward to competency
 - If the clerk or jury finds by a preponderance of the evidence that the ward is competent, the clerk shall enter an order adjudicating that the ward is restored to competency.
- G.S. § 35A-1130

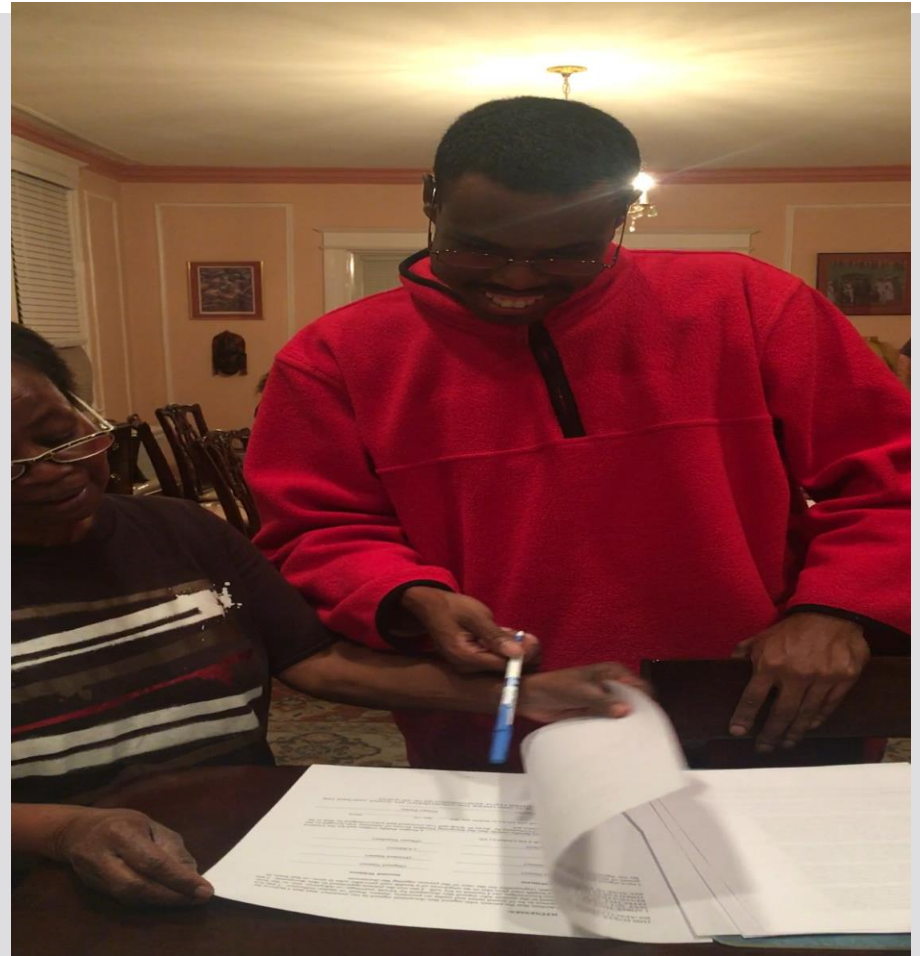
DOESN'T THAT MEAN...

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 “meet essential requirements” for taking care of 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



IT IS HAPPENING

- Laws in Maine, Tennessee, Texas, Delaware, Wisconsin, Missouri, Alaska, Washington DC, Nevada, Indiana, Rhode Island, recognizing/empowering Supported Decision-Making
- National Resource Center for Supported Decision-Making – www.SupportedDecisionMaking.Org
- Projects in South Carolina, Tennessee, New York, Kentucky, California, Washington, Nevada, North Carolina, Maine, Massachusetts, Florida, Georgia, and others focused on increasing access to Supported Decision-Making

MOVING FORWARD WITH SUPPORTED DECISION- MAKING

EVERYONE HAS THE SAME GOAL

We **ALL** want “a foundation that will foster a lifetime of opportunity and happiness.”

“Many of the means to achieving those outcomes are the same: enrollment in post-secondary education, vocational training programs, experiencing work, and developing social networks that foster long-term meaningful relationships and opportunity for continued growth.”

- Gustin, 2015

HOW DID YOU GET TO SELF-DETERMINATION?

If you're a person without disabilities, how did YOU

- Develop short/long term goals
- Identify opportunities
- Complete college applications
- Write a resume
- Get a job

“Most likely all of these experiences happened with support, either from your family or mentors.”

Gustin, 2015

A CRITICAL DIFFERENCE

- **People without disabilities:** “students . . . and families typically navigate with the assistance of a guidance department and the parent’s personal experience”
- **People with disabilities:** “Figuring out who the different service provider representatives are and what their roles are can take on a life of its own that often overwhelms families, mostly because the different service systems are not always clear on what their roles are or get into territorial role definitions that impact forward progress and planning.”
 - Gustin, 2015

THE PROBLEM:

LACK OF COORDINATION

The “fragmented system of services . . . contributing to the failure . . . to prepare [people with disabilities] for the future.” - Katsiyannis, deFur, & Conderman, 1998

“Too often, systems serving [people] with disabilities operate in “silos,” focused only on what they provide and unaware of what others do. Worse, some providers engage in territorial “battles” that duplicate or cancel out others’ efforts.” – Gustin & Martinis, 2016
www.ApostropheMagazine.Com

THINK ABOUT IT

Special Education, Vocational Rehabilitation,
Medicaid Waivers, Mental Health Services,
Adult Services

ALL can address

- Education
- Independent Living
- Health Care
- Community Integration

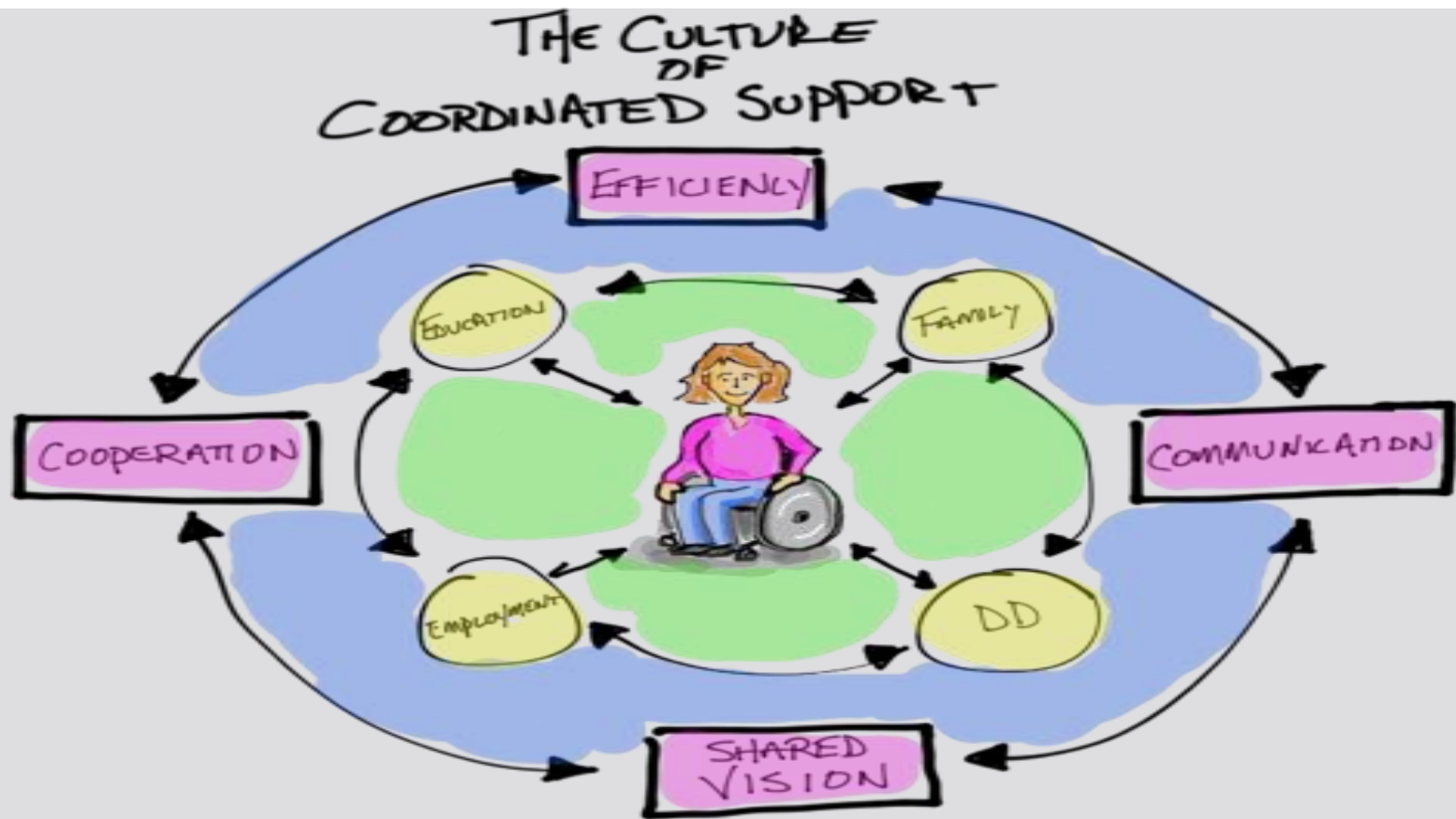
SO WHY ARE THEY NOT MORE COORDINATED?

THE SOLUTION: CREATING A CULTURE OF COORDINATED SUPPORT

“We must create cultural change by moving away from separation and silos. Instead, individuals, families, and providers must work together to empower people with disabilities to live independent, productive, and community-included lives. We call this a Culture of Coordinated Support.”

- Gustin & Martinis, 2016

How It Looks



OPPORTUNITIES FOR SDM AND COORDINATED SUPPORT 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

Article of Faith

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

Getting There: The Individuals with Disabilities Education Act

“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)

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).

Start Early

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

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

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

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."

Creating and Reaching Those Goals: The Student Led IEP

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

DOESN'T THAT SOUND LIKE

SUPPORTED DECISION-MAKING?

Why Guardianship?

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

- Kapp, 1999

Learning to “Take Care” : SpEd 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)

Transition Services

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

YOU HAVE FIVE YEARS

- 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”

Article of Faith

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?

THERE IS:

Vocational Rehabilitation (VR) Services provide services and supports to help people with disabilities:

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

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

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

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

PLAN TO SUCCEED

The Individualized Plan for Employment (IPE)

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

34 CFR 361.46

YOUR TURN

What are some of the things that keep people with disabilities from working?

THINK BROADLY

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

“INFORMED CHOICE”

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

DOESN'T THAT SOUND LIKE

**Supported Decision-Making?
The Student Led IEP?**

CULTURE OF COORDINATED SUPPORT

SPeD AND VR

- The Workforce Innovation and Opportunity Act requires VR to “significant emphasis on the provision of services to youth with disabilities”
 - U.S. Department of Education, 2014
- Federal law requires VR to become involved in Special Education services “as early as possible”
 - 34 C.F.R. § 361.22
- VR must attend IEP and ISP meetings if invited
 - 34 C.F.R 361.48

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

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)

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

DOESN'T THAT SOUND LIKE A JOB FOR

Supported Decision-Making!

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

EXAMPLE: POWER OF ATTORNEY

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.”**

MEDICAL ADVANCED DIRECTIVE

“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.”

COORDINATION OPPORTUNITY

“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>

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

DOESN'T THAT SOUND LIKE

Supported Decision-
Making?

The Student-Led IEP?

Informed Choice?

Informed Consent?

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

FINANCIAL COORDINATION: SPENDING 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.**

FINANCIAL COORDINATION BANKING AUTHORITY

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.**

EXAMPLE: END OF LIFE PLANNING

“The Conversation” and “Five Wishes”

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

BRINGING IT TOGETHER: A COORDINATED SUPPORT PLAN

- **Review!** Go through each area of the individual's life.
 - Example: Financial, Medical, Social, Employment
- **Brainstorm!** Does the person need support in these areas?
 - If so, talk about what support could help, who could provide it, and how
- **Write!** As you develop support solutions, create a written plan for the person and team to use
- **Attach!** Include it as part of the person's IEP, ISP, IPE, and other plans

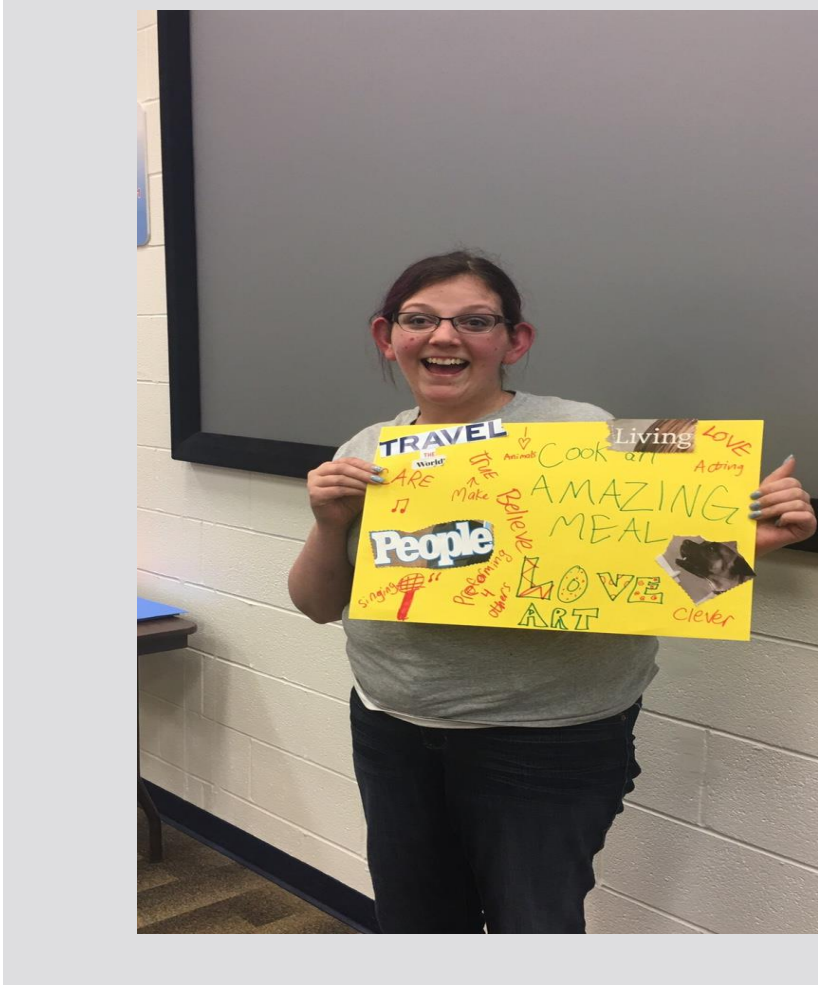
MAKING IT HAPPEN: DREAM-INSPIRED PLANNING

- Coordinating and collaborating to create support plans that build on the person's dreams.
- Goals and Objectives are created by working with the person to identify their dreams, the values that make them up, and the education, employment, independent living, and other goals that match up to them

DREAM-INSPIRED PLANNING: THREE STEPS

- **Dream:** The person identifies and communicates his/her dreams
- **Dig:** Conversations between the person and the support coordinator about his/her dreams, the values and visions that make them up, and the implications of them
- **Develop:** The person and support coordinator develop program goals and objectives that are consistent with and move the person toward their dreams

DREAMING



IT IS HAPPENING

PICKAWAY COUNTY AND PERRY COUNTY, OHIO, AND RUTLAND, VERMONT

- “Successful Transitions Project”
- Collaboration between School, VR, DD Service provider
- Identifying students at risk of guardianship and putting supports in place to help them live independently using SDM
- In Vermont:
 - 86% Agreed that the Program helped prepare students for life after high school;
 - 100% Agreed that the Program improved the supports provided to students;
 - 73% Agreed that it was an easier process
 - 93% Agreed that the Program increased the amount of supports students received;
 - 100% Agreed that the Program helped identify student needs
 - 100% Agreed that the Program provided better supports to meet student needs

BUT IT WILL ONLY HAPPEN

If we recognize, respect, and
protect **EVERYONE'S**
Right to Make Choices.

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.”

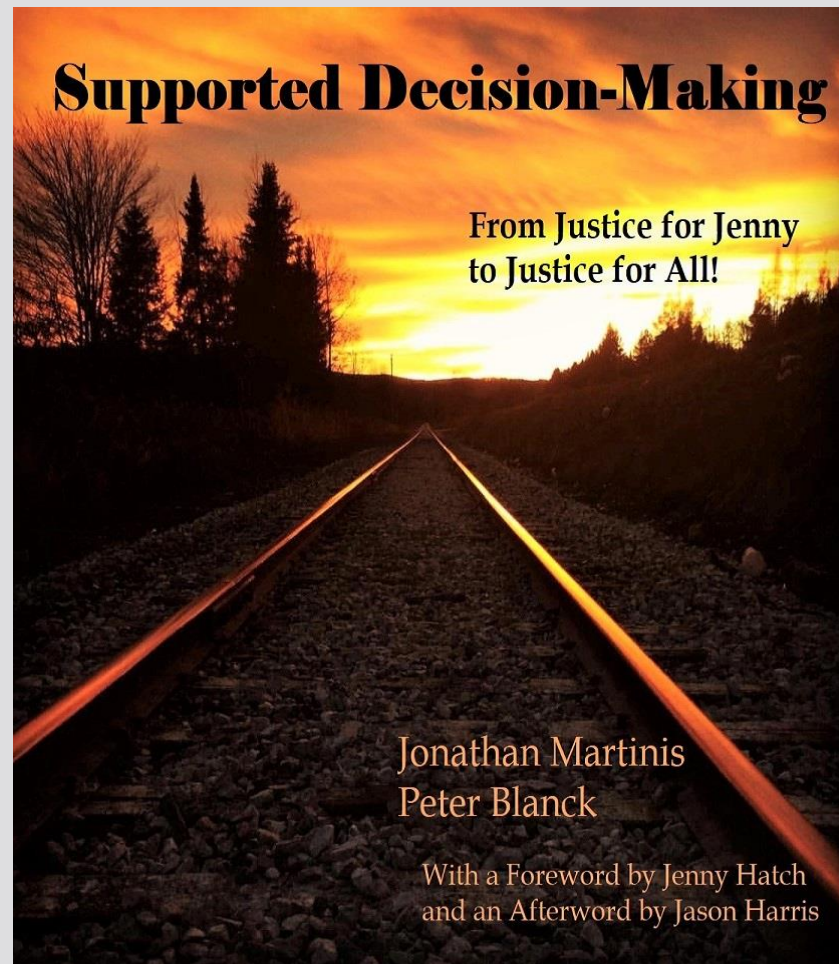
- Stephen R. Donaldson

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

RESOURCE: SDM GUIDEBOOK



JOIN THE CONVERSATION

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

The Burton Blatt Institute at Syracuse University: www.bbi.syr.edu

Jonathan Martinis: SomethingElseJM@Gmail.Com

“Supported Decision-Making: From Justice for Jenny to Justice for All”: https://www.amazon.com/Supported-Decision-Making-Justice-Jenny/dp/1693400251/ref=sr_1_1?keywords=supported+decision+making+martinis+jenny&qid=1573662603&sr=8-1