

**Supported Decision-
Making**

**From Theory to Practice:
Special Education and
Vocational Rehabilitation**

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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

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

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 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

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

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, community integration, and safety.

- Powers et al., 2012; Shogren, Wehmeyer, Palmer, Rifenburg, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003; 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



SO, WHERE DO WE GO FROM HERE?

If:

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

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

A WAY FORWARD: SUPPORTED DECISION-MAKING

“a recognized alternative to guardianship through which people with disabilities use friends, family members, and professionals to help them understand the situations and choices they face, so they may make their own decisions without the “need” for a guardian.”

- Blanck & Martinis, 2015

A Way to Self-Determination: 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)

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?

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).

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

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

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!

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."

Your Turn: Writing Goals

- Write an "I Statement" to improve this goal:

"The Student will reduce the number of times she is tardy by 50%."

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

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

SDM and Self-Determination: Sounds Great, How Do I Get it?

Ask Early

- What is your school district's policy on developing self-determination and decision-making skills?
- Request self-determination goals
- Student Involved in IEP Process from Day 1

Evaluations

- Parents have a right to request evaluations for **ANYTHING**.
 - 20 USC 1415(b)(1)
- We already know that FAPE includes “special education and related services designed. . . **prepare them for . . . independent living.**”
 - 20 U.S.C. § 1400(d)(1)(A)

“Dear School”

“I believe **STUDENT** has limitations in self-determination and decision-making that are keeping **STUDENT** from making educational progress, including preparing **STUDENT** for independent living. Pursuant to 20 USC 1415(b)(1) and I ask that you conduct an evaluation of **STUDENT** to determine if this is so and what services will help **STUDENT** overcome the limitations.”

If You Don't Like the Results

“I disagree with the results of your self-determination, decision-making skills evaluation. I still believe that **STUDENT** has limitations in those areas that are preventing **STUDENT** from making educational progress. Therefore, pursuant to 34 C.F.R. 300.502, I request an Independent Educational Evaluation at public expense”

SELF-DETERMINATION GOALS

- Research shows that creating and implementing such 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

But, Wait

WHAT DOES THIS HAVE TO DO
WITH GUARDIANSHIP AND
SUPPORTED DECISION-MAKING?

REMEMBER JENNY?

“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.”

Doesn't that Sound Like SDM and the Student Led IEP?

“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

SDM Is Consistent with Best Practices

Schools should help students improve their “goal setting, problem solving, decision-making and self-advocacy skills . . . and [provide] opportunities for students to use these skills.” - Wehmeyer & Gragoudas, 2004.

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 of Yourself”: 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 Planning

Starts: “Beginning not later” than the year the student turns 16

- 20 U.S.C. § 1414(d)

Continues: At least until student is 21

- 34 CFR §300.101

TRANSITION ACTIVITIES

- Taking part in home, school and community activities that relate to their interests
- Identifying and networking with people and agencies that can provide services and supports
- Identifying short and long term goals and providers of information, services and training to help reach them

(Waters, D., Zanghi, M., Ansell, D., Armstrong, E., & Sutter, K., 2010).

TRANSITION WHO'S WHO

- The state Vocational Rehabilitation (VR) agency - help with supports and services designed to help people with disabilities gain and maintain employment.
- State or local agencies providing services to people with developmental disabilities. These include the Protection and Advocacy System, University Center for Excellence, and DD Council
- Independent Living Centers (ILCs). Education, advocacy training, plans for self-sufficiency, counseling, service coordination and other services designed to help people with disabilities live as independently as possible.
- Representatives from the Social Security Administration who can provide information, supports and services to help people with disabilities become employed or maintain employment.

deFur (2010)

TRANSITION IS IT'S OWN PLAN!

Should include:

- “interagency agreements that clearly articulate roles, responsibilities, communication strategies and other collaborative actions that enhance . . . program development and service delivery.” (Kohler, P., & Field, S., 2003).
- Detailed plans overcome the “fragmented system of services within high schools and adult services . . . contributing to the failure of special education to prepare youths for the future.” (Katsiyannis, A., deFur, S., & Conderman, G., 1998).

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 are:

“designed to assess, plan, develop, and provide vocational rehabilitation services for individuals with disabilities . . . so that such individuals may prepare for and engage in gainful employment”

Rehabilitation Act of 1973, § 720(a)(2).

WHAT'S IT ALL ABOUT?

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)

WORK?

What does THAT have to do with
guardianship and Supported
Decision-Making?

WHAT IF...

The skills you need to work are
the **SAME** ones you need to
avoid guardianship?

WELL, THEN...

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!

THAT MEANS

VR programs have more potential to do more good for people with disabilities than just about any other program.

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.

34 CFR 361.46

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

YOUR JOB

Not just one of “the Four F” jobs:

- Food
- Filth
- Filing
- Flowers

THE PLAN

IPE lays out the services and supports you need to reach your goal.

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

IF IT'S WORK RELATED, VR CAN PROVIDE IT

- Temporary Rent
- Clothing
- Therapy Services
- Dental Work

MORE THAN “JUST” WORK

Self-Determination – Control of your OWN life

People with more Self-Determination are:

- More Independent
- More Integrated in their Communities
- Healthier
- Better Employed at Higher Wages!

WAIT A SECOND...

“This all sounds great, but what does it have to do with Supported Decision-Making?”

“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?

“[P]eople 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.”

SOUND FAMILIAR?

Remember Self-Determination:

“causal agents . . . actors in their lives instead of being acted upon”

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

**Informed Choice=Supported
Decision-Making=Self-
Determination**

WHY IS THIS IMPORTANT?

Why are people put under guardianship?

Perception that people with disabilities and older adults cannot “take care of themselves in a manner that society believes is appropriate”

Kapp, M. (1999).

SO WHAT IF...

Inability to “take care of yourself” is what’s keeping you from working?

Employment-based “life skills” like:

- Self-care
- Organization
- Communication
- Interpersonal Skills

WAIT...HOW IS THAT AN EMPLOYMENT-BASED SKILL?

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?

THEREFORE...

If your “life skills” limitations are related to your disability and make it harder for you to prepare for, get, or keep work:

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

How?

Through services and supports **YOU** choose to help you overcome the things keeping you from working – like:

- Technology
- Medical and Mental Health Care
- Education and Training programs

PUTTING IT TOGETHER

Work with the VR program to:

- Identify jobs and job types matching your skills and interests.
- ID the things keeping you from preparing for, getting, or keeping that type of job
- Access the services – like “vocational and other training, including . . . personal and vocational adjustment services” - that can help overcome them.

WHILE YOU'RE DOING THAT...

- 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

SPED AND VR

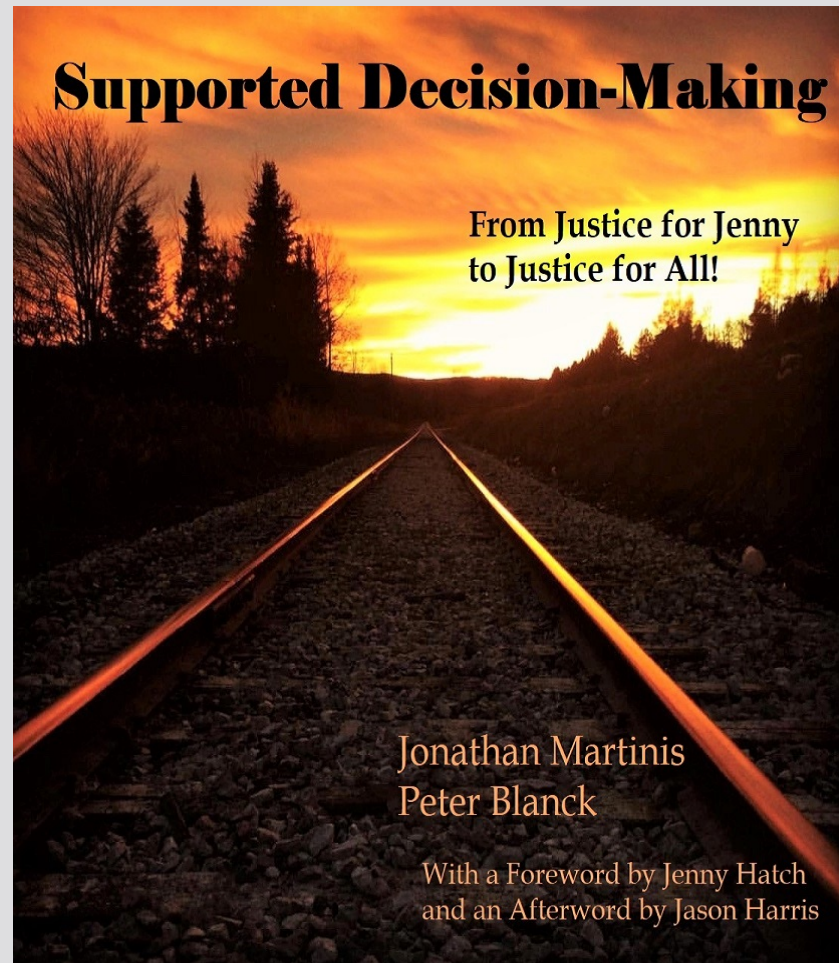
USING THEM TOGETHER

- 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

SO USE THEM TOGETHER!

- To develop independent living skills
- To develop community participation skills
- To link to services
- To build and practice self-determination and Supported Decision-Making
- To **CLOSE THE ON RAMP TO GUARDIANSHIP**

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

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“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