

# **Creating a Culture of Coordinated Support**

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Martinis

# ARTICLE OF FAITH: 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

# GETTING THERE: 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 disabilities who exercise greater self-determination have a **better quality of life**, more independence, and more community integration - Powers et al., 2012; Shogren, et al, 2014

# GETTING TO SELF-DETERMINATION: 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

# 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

# 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](http://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

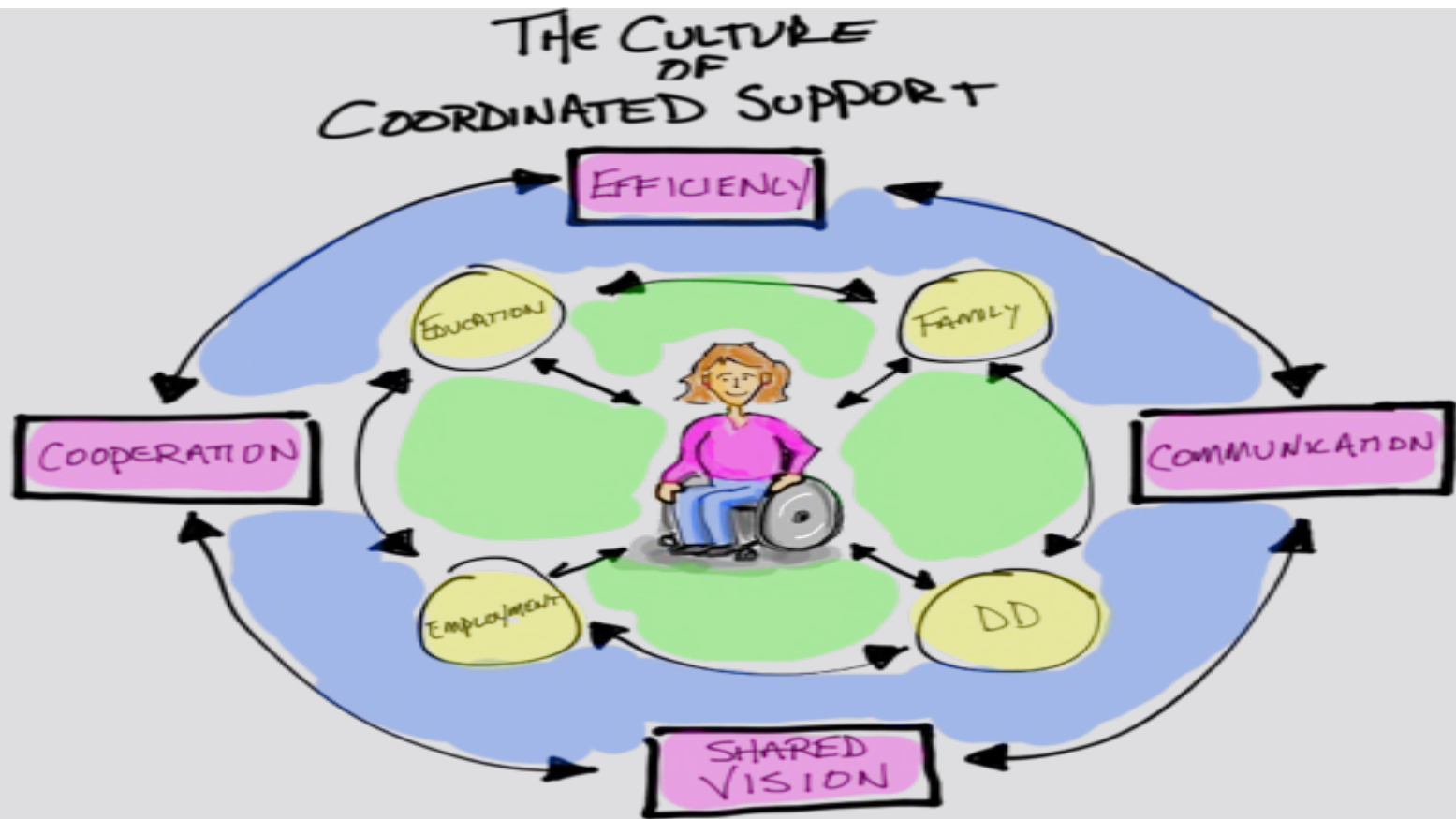
**SO WHY ARE THEY NOT MORE COORDINATED?**

## **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

# Getting To CCS: The Individuals with Disabilities Education Act

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)

# 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 unless its TRULY necessary!



# 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

# 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: Writing 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**

# 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



# 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

# 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” 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)

**NEW HAMPSHIRE BEGINS AT 14**

**Continues:** At least until student is 21

- 34 CFR §300.101

# 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 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!

# ELIGIBILITY FOR VR

Your are eligible for VR if you

- Have a disability
- Want to Work
- Your disability makes it hard/harder to work

AND

- VR services will help you work.

If you receive SSI/SSDI you are **presumed eligible!**

34 CFR 361.42

Find your local VR office here:

<https://www.education.nh.gov/partners/vocational-rehabilitation>

# 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.
- The services and supports you need to reach your goal.
  - 34 CFR 361.46

# 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**

# WON'T WORK MAKE ME LOSE MY BENEFITS?

- Budgeting and money management are extremely important to people who receive public benefits like Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and Medicaid.
- In general, you cannot have more than \$2,000 in money and assets if you receive benefits
- As a result, many people are afraid to work because they think they'll lose the medical and other supports they need to stay healthy and live independently. - Morris, Rodriguez, & Blanck, 2016.

# BENEFITS PLANNING AND VR SUPPORTS

- VR agencies can provide *benefits counseling* to help people understand the impact working may have on their SSI, SSDI, Medicaid, and other public benefits.
- This can include budgeting, keeping track of your assets, and reporting income to SSA
- If you or someone you support are receiving public benefits and working with VR to find employment, you may want to ask the agency for benefits counseling as a part of an IPE.
- Benefits counselors are also known as Community Work Incentive Coordinators or CWICs
- You can ask VR to either provide benefits counseling or refer you to and pay for a CWIC

# 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

# MORE COORDINATION:

## PRE-EMPLOYMENT TRANSITION SERVICES

- *Pre-ETS are available for ALL students with IEPs or 504 Plans*
- *Pre-ETS include:*
  - Job exploration counseling;
  - Work-based learning experiences, which may include in-school or after school opportunities, or experience outside the traditional school setting (including internships), that is provided in an integrated environment in the community to the maximum extent possible;
  - Counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs at institutions of higher education;
  - Workplace readiness training to develop social skills and independent living; and
  - Instruction in self-advocacy (including instruction in person-centered planning), which may include peer mentoring (including peer mentoring from individuals with disabilities working in competitive integrated employment).
- **VR MUST COME TO IEP MEETINGS IF INVITED**

- 34 CFR 361.48

# 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?



# 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

Use Supported Decision-Making across systems to Identify and Coordinate

- Opportunities and Options
- Supporters and Teams
- Goals, Supports, and Services

# CREATING 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

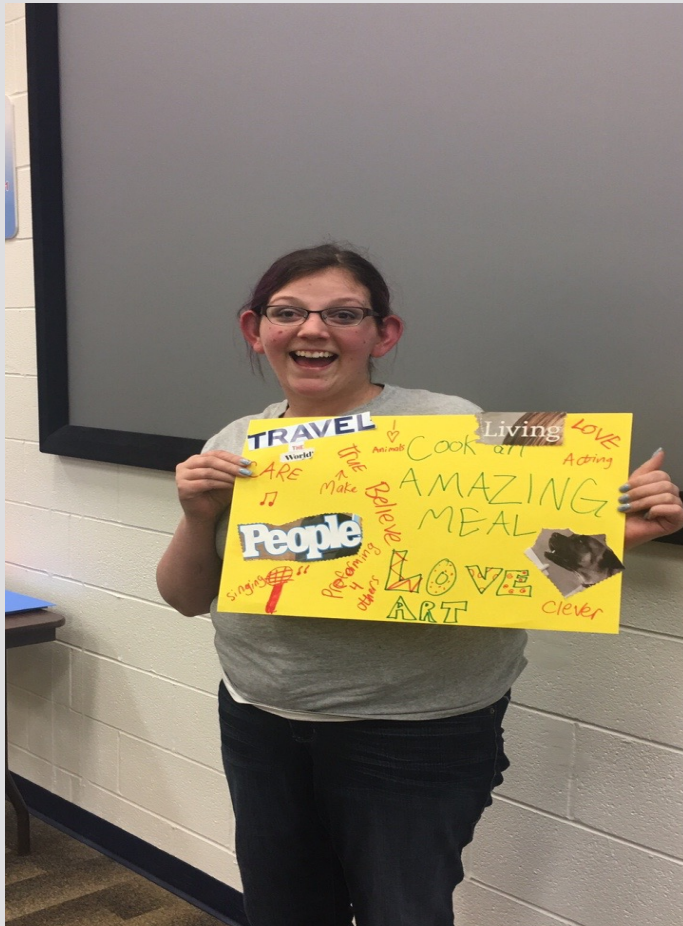
# MAKING IT HAPPEN: DREAM-INSPIRED PLANNING

- 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 CAN HAPPEN: PROJECT RENEW

Provided young adults with coordinated services including employment planning and training as well as education in independent living skills and social skills- Malloy, 2013.

- First year of program
    - 93% of participants found employment
    - 69% maintained employment for more than 6 months
  - 2 years after program
    - 94% either completed high school or were involved in a high school program
    - 75% were enrolled in post-secondary education
    - 83% found employment
- Hagner, Cheney, & Malloy, 1998

# IT IS HAPPENING: RUTLAND, VERMONT

- High School, VR Agency, and Waiver provider collaborated with students and families
- Students made Dream Boards
- Agencies created joint plans with common goals and objectives
- Plans were implemented and updated as necessary over one year.
- After the year, participants were surveyed:
  - 86% Agreed that the Program helped prepare students for life after high school;
  - 73% Agreed that the program was easier than the usual methods
  - 100% Agreed that the Program improved the supports provided to students;
  - 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!

“If we create a Culture of Coordinated Support . . . service providers will . . . help people with disabilities dream and lead lives of independence and meaning. If we create a Culture of Coordinated Support, people with disabilities will have the same opportunities for success and security as their nondisabled peers. If we change the culture, we will change the world!”

Gustin & Martinis, 2016

# JOIN THE CONVERSATION

The National Resource Center for  
Supported Decision-Making:  
[SupportedDecisionMaking.Org](http://SupportedDecisionMaking.Org)

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