Creating a Culture of Coordinated Support

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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

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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

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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

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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

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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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Research

In a study, young adults who used Supported Decision-Making showed:

- Increased independence, confidence, and decision-making abilities
- Made better decisions
- Had enhanced quality of life

- Martinis & Beadnell, 2021

http://supporteddecisionmaking.org/node/488

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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

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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

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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

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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?

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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

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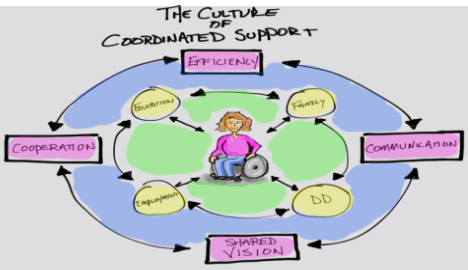
How It Looks



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Coordination and Communication are Critical

Different agencies and professionals bring unique viewpoints and expertise to each issue.

For example, if a person's independent living goal is to have his or her own apartment:

- Education professionals may help the person identify and take part in classes, community programs, or adult services to increase his or her daily living skills.
- A VR counselor may help the person identify and choose job goals and training that maximize income to pay for rent and living expenses;
- A Board of DD professional may help identify independent living supports like health care management and transportation;

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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

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Coordination is ALREADY required

- Special Education Transition Services must be "a coordinated set of activities;" 20 USC 1401(34)
- VR programs must become involved in Special Education services "as early as possible" and avoid duplicating efforts from other agencies; 34 CFR 361.22, 34 CFR 361.53
- Waiver and other Person Centered Plans must include support from caregivers, facilitators, case managers and others that the person has identified "as playing an important role in his or her life;" - CMS, 2016and

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Examples Of CCS

- A school and Board of DD collaborating with a student on education, community participation, and employment supports;
- A school, VR, and Board of DD coordinating Transition services with a young adult including education, employment, and independent living supports;
- An ABLE Account holder, VR, and Board of DD collaborating to develop and implement benefits planning, budgeting, and other money management supports;
- School, VR and a Board of DD sharing responsibilities with a person to develop employment supports; and
- School and Board of DD coordinating with a person on independent living supports.

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SDM is the Key To CCS

- Special Education programs must use the Student Led IEP or other methods so students and educational professionals can develop goals and supports that meet the "needs that result from the child's disability" – 20 USC 1414
- VR agencies must provide people with Informed Choice by giving them information about available jobs and services so they can choose their employment goals and the supports they need to achieve them. – 34 CFR 361.52
- Boards of DD and Waiver programs support people to develop Person Centered Plans with "individually identified goals and preferences." – CMS, 2014

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Getting To CCS: 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)

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What 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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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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Creating and Reaching 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

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Coordination Opportunity: 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)

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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

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YOU HAVE 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"

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COORDINATED SUPPORT OPPORTUNITY: VOCATIONAL REHABILITATION

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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WHAT IF…

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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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?

The Student Led IEP?

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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

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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

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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

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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?

The Student Led IEP?

Informed Choice?

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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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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 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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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: ABLE Accounts

Purpose of the ABLE Act is:

"supporting individuals with disabilities to maintain health, independence, and quality of life."

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Example: End of Life Planning

"The Conversation" and "Five Wishes"

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

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Bringing It Together

Use Supported Decision-Making across systems to Identify and Coordinate

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

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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

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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

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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

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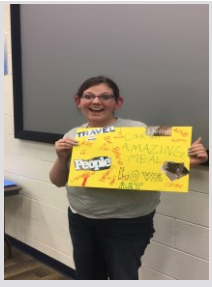
Dreaming



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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

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It IS Happening Pickaway County and Perry County, Ohio

- "Successful Transitions Project"
- Collaboration between School, VR, and County Board of DD
- Identifying students at risk of guardianship and putting supports in place to help them live independently

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Successful Transition Project

- School, Board, and VR meet with student and parents to create joint plans
- The plans have common goals and objectives
- In the meetings, they student, family, and agencies, choose supports and services and who is best to implement them

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CCS Results

Mansfield Senior High School in Ohio encouraged 30 students to create Dream Boards to share their dreams with their teachers and counselors. Two teachers commented on the experience:

- It was a wonderful opportunity for our special needs students. The level of engagement by every student in our program was incredible. Equally terrific was for our staff to hear and share in our students' dreams and to hear them express their career passions. Many of our staff were brought to tears when we heard what our students shared. We sincerely hope that we can continue to stir and form our students' career dreams. _ Richland County Board of Developmental Disabilities, 2017

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CCS Results

Two case managers from a local Developmental Disabilities Board "had the opportunity to observe first-hand how powerful the dream boards can be."

- During a home visit with a family, a parent explained her daughter brought home a dream board from school. The parent expressed there were passions on the dream board her daughter shared that she was unaware of. The parent had no idea that her daughter was interested in working at Starbucks - Richland County Board of Developmental Disabilities, 2017.

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CCS Results

Students using Dream Boards in IEP meetings

"The student shared her dream board with the team and pointed to each picture to describe her dreams. Each item she shared was added to her IEP as these were new things that the student wanted for her future. The student shared her dream job is to be a fashion designer. She had additional dreams of being married, owning a car, making money and to have friends. - Richland County Board of Developmental Disabilities, 2017.

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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

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BUT IT WILL ONLY HAPPEN

If we recognize, respect, and protect **EVERYONE'S**

Right to Make Choices.

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REMEMBER THE CHALLENGE

EVERY great advance in civil rights fundamentally changed the way "things have always been"

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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

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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

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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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