

<h2>Creating a Culture of Coordinated Support</h2>	<p>Jonathan Martinis</p>
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<p>ARTICLE OF FAITH: EVERYONE HAS THE SAME GOAL</p>
<p>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</p>
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<p>GETTING THERE: SELF-DETERMINATION</p>
<ul style="list-style-type: none">▪ Life control▪ People’s ability and opportunity to be “causal agents . . . actors in their lives instead of being acted upon” <p>- Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000</p>
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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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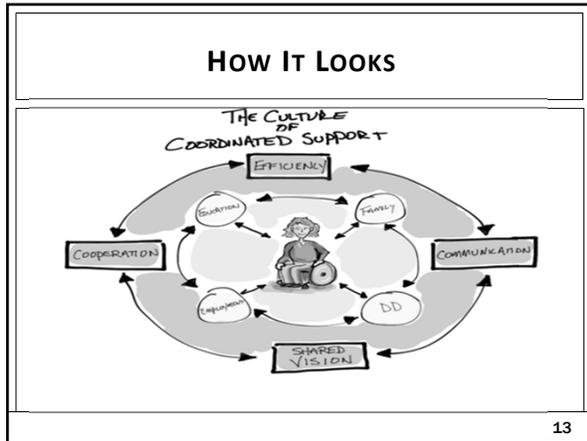
**THE SOLUTION:
CREATING A CULTURE OF COORDINATED SUPPORT**

“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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- ### 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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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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DOESN'T THAT SOUND LIKE

Supported Decision-Making?

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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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**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
- Pre-Employment Transition Services designed to increase education, employment, and self-advocacy opportunities for students with disabilities
- 34 C.F.R. 361.48
- VR must attend IEP and ISP meetings if invited
- 34 C.F.R 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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ACCESSING SUPPORTED DECISION-MAKING THROUGH MEDICAID: EPSDT

Early and
Periodic
Screening
Diagnosis
Treatment

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THE BASICS
<ul style="list-style-type: none">■ EPSDT is designed to identify and treat problems EARLY before they worsen.■ Available to ANYONE receiving Medicaid (through "State Plan Option," HMO, or Waiver) who is under 21■ You do not have to enroll - it is NOT a separate Medicaid program

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IN PRACTICE: WHAT IT COVERS
<p>ANYTHING that can conceivably be covered by Medicaid, whether or not Florida covers it. If some state COULD cover it to fix a medical problem, help it, or keep it from getting worse, Florida MUST cover it under EPSDT.</p> <ul style="list-style-type: none">■ Example: Virginia did not cover most dental care under Medicaid but other states do. So, Virginia MUST cover dental care for children receiving EPSDT.

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ESPST AND SELF-DETERMINATION
<p>So, if child's disability causes him or her to have difficulty "taking care of [him or herself] in a manner that society deems appropriate," EPSDT must cover supports and services to help the child overcome this.</p>

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COORDINATION OPPORTUNITY: SPECIAL EDUCATION AND EPSDT

If a school is a Medicaid Provider, any medical services and supports in an IEP are covered by Medicaid.

<https://www.cms.gov/research-statistics-data-and-systems/computer-data-and-systems/medicaidbudgetexpendsystem/downloads/schoolhealthsvcs.pdf>

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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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OPPORTUNITY: ABLE ACCOUNTS

- To live independently, many people rely on public benefits like Medicaid, SSI, and SSDI
- To qualify for Medicaid/SSI, you generally may not have more than \$2,000 of countable assets. Earnings of more than the substantial gainful activity (SGA) level can also affect eligibility for these programs.
- If families provide financial or “in-kind” support, the person may be disqualified or have benefits reduced.

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ABLE BASICS

- Like 529 Accounts for Education
- If people receive public benefits or COULD if they applied, they are eligible for ABLE
- Family, friends can contribute up to \$15,000 per year into an ABLE account
- ABLE account money can be withdrawn, tax free, to pay for housing, transportation, healthcare and other expenses
- Money in an ABLE account **does not** affect eligibility for Social Security or Medicaid/Medicare (if there is more than \$101,999 in account, SSI benefits will be suspended, but still receive Medicaid).
- For more info, including how to enroll, see www.ABLENRC.Org

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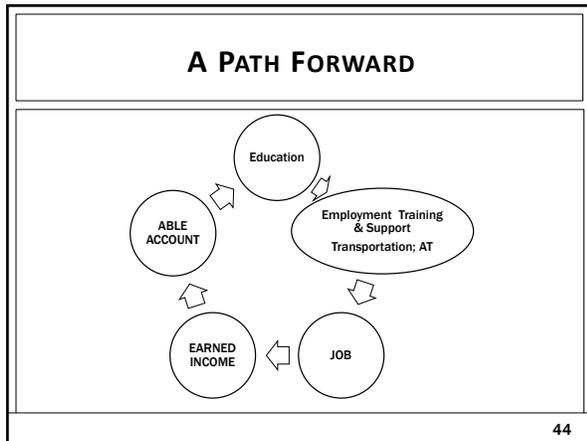
SPECIFICALLY

ABLE Account funds can be used for:

- **Education**—including tuition for preschool thru post-secondary education, books, supplies, and educational materials related to such education, tutors, and special education services.
- **Housing**—including rent, mortgage payments, home improvements and modifications, maintenance and repairs, real property taxes, and utility charges.
- **Employment Support**—including expenses related to obtaining and maintaining employment, including job-related training, assistive technology, and personal assistance supports.
- **Health**—including premiums for health insurance, medical, vision, and dental expenses, habilitation and rehabilitation services, durable medical equipment, therapy, respite care, long term services and supports, and nutritional management.
- **Transportation**—including the use of mass transit, the purchase or modification of vehicles, and moving expenses.
- **Other Life Necessities**—including clothing, activities which are religious, cultural, or recreational, supplies and equipment for personal care, community-based supports, communication services and devices, adaptive equipment, assistive technology, personal assistance supports, financial management and administrative services, expenses for oversight, monitoring, or advocacy, funeral and burial expenses.

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BEFORE ABLE, SPECIAL NEEDS TRUSTS

- Like ABLE, people could set aside funds for an individual with a disability.
- **BUT** – money in SNT is taxable.
- **BUT**, SNT funds could not buy anything that Medicaid paid for – so people who need more than what Medicaid pays for were out of luck.
- **BUT**, SNTs can be expensive. Not all states offer low cost pooled SNT option.

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THE BIG ONE

In a Special Needs Trust:

Trustee Decides How The Money is Spent

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ABLE ACCOUNTS AND SELF-DETERMINATION

In ABLE Accounts, the person with disabilities decides how the money is spent

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THE WHOLE POINT

Purpose of the ABLE Act is: “supporting individuals with disabilities to maintain health, independence, and quality of life.”

SO, If Increased Self-Determination=Improved Health, Increased Independence, and Better Quality of Life . . .

Shouldn't ABLE Accounts Increase Self-Determination?

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DOESN'T THAT SOUND LIKE A JOB FOR

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 without the "need" for a guardian."

- Blanck & Martinis, 2015

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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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**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: RUTLAND, VERMONT

- High School, VR Agency, and Waiver provider collaborated with students and families
- Agencies created joint plans with common goals and objectives
- After one 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

Martinis, et al, 2019

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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**

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JGMartinisLLC@Gmail.com**

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