



**Bringing it All Together: Creating
a Culture of Coordinated Support**

PEATC's Transition to Adulthood Series



Bringing it All Together: *Creating a Culture of Coordinated Support*

Why does it seem like everyone thinks people with disabilities can't "take care of themselves"¹ and *always* need guardians to make decisions for them? Too often, parents of people with disabilities are told by teachers, lawyers, doctors, and other people they trust that they *have* to get guardianship² and aren't told about any other options.³

In this brochure, we'll tell you about an option called Supported Decision-Making and how people with disabilities can use it to bring together the services they need to "take care of" themselves and lead their best, most independent lives.



To get the most out of this brochure, we recommend that you read our other brochures on Supported Decision-Making first:

- [Is Guardianship My ONLY Option?](#)
- [Learning to be Independent: Supported Decision-Making in Special Education Programs](#)
- [What Comes Next? Supported Decision-Making and Special Education Transition Services](#)
- [Getting to Work: Supported Decision-Making in Vocational Rehabilitation](#)
- [Taking Care, Taking the Lead: Supported Decision-Making and Your Health](#)
- [My Money, My Choices: Supported Decision-Making and Managing Your Money](#)

Supported Decision-Making:

What is It?

Supported Decision-Making is getting help when you need it, from people you trust, so you can make your own decisions.⁴

Isn't that how we *all* make decisions? When you have to make a tough choice, or a decision about something you're not familiar with, or just want to "talk it out," what do *you* do?

You get help, don't you? You may ask a friend for advice or a professional for information, or you may have "go to" people in your lives that you talk to about specific subjects. They help you "think through" the issues, discuss the "pros and cons" to clear up your choices, and identify solutions. That way, you can understand your options and choose the one that's best for you.

When you do that, you're using Supported Decision-Making. People you trust give you support, so you can decide. *That's it.*

The Problems with “Silo Systems”

Young adulthood is a challenging time for people with disabilities. When they should be taking the first steps to living and working independently, they may face a “fragmented system ... within high schools and adult services” that doesn’t prepare them for the future.⁵

Think about it: doesn’t it seem like sometimes you spend so much time trying to figure out *what* kinds of service are available and *who* can help that you don’t know if you’ll ever *actually* get what you need? Or that no one knows who you should talk to? It’s like you’re stuck in a silo with no one to show you the way out.

In a *silo system*, people with disabilities don’t get what they need. Programs that should be working together don’t. Providers don’t communicate with each other and give completely different advice. People with disabilities and their families never get a *real* chance to get the supports they need to live as independently as they can.

Maybe that’s why so many believe that people with disabilities can’t take care of themselves – *because they don’t get what they need to do it.*⁶



Breaking Down the Silos: *the Culture of Coordinated Support Model*

We must change “the system” and break down the silos to make sure people with disabilities can get what they need to live their best lives. We need a system where people with disabilities, families, programs, and providers work and develop plans and supports together. Researchers and scholars call this the Culture of Coordinated Support Model (CCS).⁷

In CCS, people with disabilities, families, programs, and providers use Supported Decision-Making to develop shared goals and objectives. In CCS, service plans and supports build on each other and are based on the what the person does well, what they need help doing, and what they want to do. That way, the person receives supports and services that are more effective and efficient.⁸

The best part is that the key principles of CCS are *already required*. For example:

- Special Education Transition Services must be “a coordinated set of activities.”⁹
- Vocational Rehabilitation programs must become involved in Special Education services “as early as possible”¹⁰ and attend Individualized Education Program (IEP) and Medicaid Waiver Person Centered Planning meetings when invited.¹¹
- Medicaid Waiver Person Centered Plans must include support and information from family members, providers, and others that the person wants involved.¹²

In other words, programs and providers should *already* be working together. CCS makes that a reality!



USING SUPPORTED DECISION-MAKING TO MAKE CCS WORK

You can use CCS whenever a person with disabilities is working with more than one program or provider. The key to CCS is people with disabilities and their supporters working together. So, programs and providers will work with the person *and* each other.

For example, in an effective CCS, people will share information with their supporters about things that are important to them, like their goals and hopes for the future. Their supporters will then work with the person and each other to develop plans and services to help them reach their goals.

Doesn't that sound like Supported Decision-Making? Isn't that an excellent example of people with disabilities working with their supporters to help them understand their choices, make informed decisions, and direct their lives?

Supported Decision-Making makes CCS work! As we've shown in other brochures, programs and providers serving people with disabilities are *already* required to help them make their own decisions about their service plans and supports:

- Special Education programs must use the Student-led IEP or other ways to help students develop their IEP goals, objectives, and services.¹³
- Vocational Rehabilitation programs have to give people information and advice so they can use Informed Choice to choose their employment goals and supports.¹⁴
- Medicaid Waiver providers must help people understand their options so they can develop Person Centered Plans with goals and services they want.¹⁵



In other words, these programs *all* use Supported Decision-Making – even if they don’t call it that - because they *all* give people information and advice so they can choose their goals, objectives, and supports. So, shouldn’t they use Supported Decision-Making to work together and help the person develop the best possible plans and supports? Wouldn’t that make it more likely that the person will reach their goals?

CREATING A CULTURE OF COORDINATED SUPPORT

If you want to create a CCS for yourself, a family member, or someone you support, we recommend the following process:¹⁶

(1) This person and supporters agree to work together.

The first step in CCS is for the person and supporters to agree to work together. This doesn't mean they have to form a new team, have more meetings, or do more paperwork. As we've discussed, they're *already* supposed to work together. CCS helps them do that.

So, start by talking with the person and their supporters about ways they can work together on their service plans and supports. Give them permission to share information and records about the person. Invite them to come to each other's meetings - for example, Vocational Rehabilitation counselors and Medicaid Waiver case managers should attend IEP meetings.

(2) The person's goals and hopes for the future are put in their service plans.

Next, the person and supporters should use Supported Decision-Making to help the person share their goals and hopes for the future. What does the person want to do? What do they want to learn? Where do they want to live and work?

These goals are the *culture* of the CCS. The person's service plans should then have supports that help the person reach their goals. For example, if the person's long-term goals are to "have my own apartment," "graduate from college," and "work with computers," their Special Education, Vocational Rehabilitation, and Medicaid Waiver plans should include those goals and supports to help the person reach them.¹⁷

(3) The service plans include the specific services each supporter will provide.

Next, use Supported Decision-Making to identify the specific supports the person needs to reach their goals. What skills do they need to learn? What could stop them from reaching their goals? Who can help?

For example, if the person's goal is to work as a computer programmer, what education or training do they need? If they want to live independently, do they need to earn more money or need help budgeting to pay rent? If they want to go to college, do they need assistive technology or personal assistance for classes? Who should help and how?

The person and supporters must work together at this stage. Different programs and providers have different experiences and can bring different ideas to help the

person. The key is for each supporter to find ways it can help the person move toward their goals.

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

- A case manager can help the person set up independent living supports like health care and transportation.
- A Vocational Rehabilitation counselor can help the person identify job goals and training so the person can earn enough money to pay their rent.
- Education professionals can help the person identify the classes and community services they need to learn independent living skills.



That way, the person will get what they need to reach their goals because each supporter will do what it does best – schools will focus on education, Vocational Rehabilitation on employment, and Medicaid Waiver and other providers such as Centers for Independent Living on independent living skills.

(4) “Check in” to make sure things are going well or make changes.

Finally, the person and supporters should schedule regular “check in” calls or meetings to share how things are going. The “check-ins” will help them build on goals and supports that are going well or change one’s that aren’t. This will help the CCS partners be more organized and focused on helping the person reach their goals.¹⁸

The Culture of Coordinated Support Model in Action: *The Successful Transitions Program*

In Vermont, Fair Haven Union High School, the Division of Vocational Rehabilitation, and Community Care Network, a Medicaid Waiver provider created a CCS called the **Successful Transitions Program**. The three agencies used Supported Decision-Making to work with

students, families, and each other. They created service plans with supports focused on the student's goals. Each partner had specific responsibilities and they had regular "check ins" to make sure things were going well and to fix things that weren't.¹⁹

After a year of the program, the students, parents, teachers, counselors, and other professionals in the CCS filled out a survey about their experiences. Their responses showed how well the CCS worked and helped students:

- 86% said the Program helped prepare students for life after high school;
- 100% said the Program improved the supports provided to students;
- 73% said the Program was an easy process;
- 93% said the Program increased the amount of services that students received;
- 100% said the Program helped identify student needs;
- 100% said the Program provided better supports to meet student needs; and
- 93% said the Program was a good use of planning meetings.²⁰



We Can Help!

If you're interested in creating a Culture of Coordinated Support, we can answer your questions or connect you with people and organizations that may be able to help. Feel free to contact us at:

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References

- 1 Kapp, M. (1999). *Geriatrics and the law: Understanding patient rights and professional responsibilities*. (p. 109). New York: Springer Publishing Company.
- 2 e.g. Blanck, P. & Martinis, J. (2015). The right to make choices: The national resource center for supported decision-making. *Inclusion* 3(1) 24-33,
- 3 e.g., Salzman, L. (2010). Rethinking guardianship (again): Substituted decision making as a violation of the integration mandated of Title II of the Americans with Disabilities Act. *U. Colo. L. Rev.*, 81, 157
- 4 Blanck and Martinis, 2015.
- 5 Katsiyannis, A., deFur, S., & Conderman, G. (1998). Transition services: Systems change for youth with disabilities? *Journal of Special Education*, 32(1), 55-61, 55.
- 6 Martinis, J. & Gustin, J. (2017). A culture of coordinated support. *The Frontline Initiative* 14(2), 14-15.
- 7 Gustin & Martinis, 2016.
- 8 Gustin & Martinis, 2016; Martinis & Gustin, 2017; Shogren, K., Wehmeyer, M., Martinis, J., & Blanck, P. (2019). *Supported decision-making: Theory, Research, and Practice to Enhance Self-Determination and Quality of Life*, Cambridge University Press (in preparation)..
- 9 20 U.S.C. §1401(34)
- 10 34 C.F.R. § 361.22 .
- 11 34 C.F.R. §361.48
- 12 Centers for Medicare and Medicaid Services (2016). FAQs concerning Medicaid beneficiaries in home and community-based settings who exhibit unsafe wandering or exit-seeking behavior. Retrieved from: <https://www.medicaid.gov/federal-policy-guidance/downloads/faq121516.pdf>
- 13 20 U.S.C. § 1414.
- 14 34 C.F.R. § 361.52.
- 15 Centers for Medicare and Medicaid Services (2014). Fact sheet: Summary of key provisions of the 1915(c) home and community-based services (HCBS) waivers final rule. Retrieved from: <https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf>
- 16 e.g. Gustin & Martinis, 2016; Martinis & Gustin, 2017.
- 17 Gustin & Martinis, 2016; Martinis & Gustin, 2017; Shogren, Wehmeyer, Martinis, & Blanck, 2019.
- 18 Gustin & Martinis, 2016.
- 19 Martinis, J., Cassidy, K., Gustin, J., Nadeau, J., & Robinson, D. (2019). Creating a culture of coordinated support: The successful transitions program. *Impact* 32(1), 19-21
- 20 Martinis, Cassidy, Gustin, Nadeau, & Robinson, 2019



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