

**Supported Decision-
Making
From Theory to Practice:
Special Education Planning
and Supports**

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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

ARTICLE OF FAITH: 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, Wehmeyer, Palmer, Rifenburg, & Little, 2014; Wehmeyer and Schwartz, 1997; Wehmeyer & Palmer, 2003

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

**SO, SUPPORTED DECISION-MAKING IS A
LOT OF WORDS FOR**

Getting help when its needed

Just like you and me

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

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>

WHY SUPPORTED DECISION-MAKING?

Endorsed by:

- US Department on Health and Human Services
- American Bar Association
- National Guardianship Association
- ASAN
- The Arc
- NAMI

Getting 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

BEFORE IDEA

As few as one in five students with disabilities received *any* type of education.

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

BEFORE IDEA

“Important adult outcomes, such as employment, independent living and community integration [were] unattainable.”

- Wehmeyer, M.L., & Schalock, R., 2001

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 needed!

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

IEP PROCESS

- IDEA requires that schools annually review students' "present levels of academic achievement and functional performance." - 20 U.S.C. § 1414; 34 C.F.R. 300.304.
- Based, in part, on that assessment, schools must develop an IEP for students that meets the "needs that result from the child's disability" - 20 U.S.C. § 1414
- IEPs must then prepare students for "for further education, employment, and independent living." - 20 U.S.C. § 1400(d)(1)(A)

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 late 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

EXAMPLE OF STUDENT LED IEP PROCESS

Sample Progression of Student-LED IEP Activities:

ADD ANOTHER STEP EACH YEAR/AS NEEDED

- Student introduces him/herself
- Student talks about him/herself and goals/what wants to be
- Student reviews IEP with teacher at start of school year
- Student reviews strengths and limitations (PLOP) including effect of disability
- Student reviews rights and obligations under IDEA
- Student takes part in pre-IEP meeting and conferences
- Students “hosts” meeting – greets and introduces everyone
- Student states purpose of IEP meeting

STUDENT LED IEP CON'T

- Student goes through sections of IEP
- Identifies disability
- Goes through PLOP, discusses class performance
- Asks others to talk about PLOP
- Reviews assessments
- Discusses his/her goals
- Works on putting goals into IEP form
- Discusses transition goals
- Accommodations needed on tests, etc
- Additional services (PT/OT etc)
- Sets date for review with teacher
- Concludes meeting

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”

ASSESSING SUPPORT NEEDS: I'M DETERMINED.ORG

Self-Determination Checklist Educator Assessment



Student Name: _____

Date: _____

Self-Determination skills help you to know

- yourself*
- your goals*
- supports you need to reach your goals*

Use the following scale to rate the statements below:

3 = almost always/most of the time
2 = sometimes

1 = rarely or never
0 = not observed

Rating				
3	2	1	0	My student sets goals to get what he/she wants or need.
3	2	1	0	My student makes plans for reaching his/her goals.
3	2	1	0	My student checks his/her progress when working toward his/her goals.
3	2	1	0	My student attends his/her IEP Meetings.
3	2	1	0	My student participates in his/her IEP Meetings.
3	2	1	0	My student knows the goals listed in his/her IEP.
3	2	1	0	At school, educators listen to my student when he/she talks about what he/she wants or needs.
3	2	1	0	At home, my student's parents listen when he/she talks about what he/she wants or needs.
3	2	1	0	My student has others in his/her life who help him/her to accomplish goals.
3	2	1	0	My student asks for help when he/she needs it.
3	2	1	0	My student knows what he/she needs, what he/she likes and what he/she enjoys doing.
3	2	1	0	My student tells others what he/she needs, what he/she likes and what he/she enjoys doing.
3	2	1	0	My student helps to make choices about the supports (educational services) and accommodations that he/she needs in school.
3	2	1	0	My student can describe his/her learning difficulties to others.
3	2	1	0	My student believes he/she has control to direct his/her life.
3	2	1	0	My student takes care of his/her personal needs (clothes, chores, meals, grooming).
3	2	1	0	My student makes friends with others his/her age.
3	2	1	0	My student can make good choices.
3	2	1	0	My student believes that working hard in school will help him/her to get a good job.

I'M DETERMINED CHECK LIST

- Review and rate on a scale of 0-3 whether the student has characteristics that demonstrate self-determination:
 - The student feels in control of his or her life;
 - The student tells people what he or she needs and wants;
 - The student makes good choices; and,
 - The student has people in his or her life that can provide support.
- IEP teams use students' "scores" to shape their educational programs and services. For example, if a student "scores" low on areas related to decision-making, the IEP team should develop goals, objectives, and services designed to help that student use SDM.

SELF-DETERMINATION GOALS

- If students have limitations in decision-making and self-determination that are preventing them from progressing toward “further education, employment, and independent living,” their IEPs should include goals and services designed to help them improve in those areas.
- Research shows that creating and implementing such goals and supports 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

EXAMPLES OF GOALS THAT INCREASE SELF DETERMINATION

- I will work with my counselor to create a budget where I have to save and spend money every month, using higher amounts of money each month
- I will work with my team to identify three jobs I am interested in
- I will work with my aid to develop strategies for how to stay calm when I feel like getting angry
- I will work with my IEP team to identify 2 community groups I'd like to be involved with

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 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

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

WAYS TO ACCESS SUPPORTS TO LEARN TO “TAKE CARE OF YOURSELF”

- Related Services
- Therapies
- Independent Living Skills
- Functional Goals

THINK BROADLY

COORDINATION OPPORTUNITY: SPECIAL EDUCATION AND EPSDT

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

<https://www.medicaid.gov/medicaid/hcbs/downloads/1915c-fact-sheet.pdf>

SELF-DETERMINATION

So, if child's disability causes him or her to have difficulty making decisions, EPSDT must cover supports and services to help the child overcome this.

This is especially true if the disabilities are likely to result in him or her being unable to "take care of [him or herself] in a manner that society believes is appropriate"

Kapp, M. (1999).

LEARNING TO “TAKE CARE”: TRANSITION PLANNING

Special Education Transition Services are

designed 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**

20 U.S.C. § 1401(34) (A)

Transition Planning

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

- 20 U.S.C. § 1414(d)

- IN RHODE ISLAND TRANSITION STARTS AT 14!

Continues: At least until student is 21

- 34 CFR §300.101

YOUTH IN TRANSITION: ONE GOAL

“The steps out of school should allow for 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

A CRITICAL DIFFERENCE

- Students without disabilities: “students . . . and families typically navigate with the assistance of a guidance department and the parent’s personal experience”
- Students 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 within high schools and adult services . . . contributing to the failure . . . to prepare youths [with special needs] for the future.”

- Katsiyannis, deFur, & Conderman, 1998

TRANSITION SERVICES ARE

A **COORDINATED** set of services:

(B) based on the individual child's needs, **taking into account the child's strengths, preferences, and interests**; and

(C) includes instruction, related services, community experiences, the development of employment **and other post-school adult living objectives**, and, when appropriate, **acquisition of daily living skills**

20 USC 1401(34)

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.
- Service Providers including agencies that provide Medicaid waiver or independent living services
- 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).

TRANSITION PARTNER: OFFICE OF REHABILITATION SERVICES

- The Workforce Innovation and Opportunity Act requires ORS to put “significant emphasis on the provision of services to youth with disabilities” - U.S. Department of Education, 2014
- Federal law requires ORS to become involved in Special Education services “as early as possible” - 34 C.F.R. § 361.22
- ORS Agency MUST attend IEP meetings if invited – 34 C.F.R. § 361.48

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

Transition: YOU HAVE SEVEN YEARS

If there are concerns the student can't "take care of him/herself," can't make decisions, or may need guardianship

Transition Services should provide:

"Instruction [and] related services" to help with the "acquisition of daily living skills"

NECESSARILY including decision-making skills like Supported Decision-Making

USE THAT TIME

- 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**

RESEARCH ON LEARNING HOW TO “TAKE CARE”

- Self-Determined Learning Model of Instruction (SDLMI) - Agran, Wehmeyer, 2000
- Students take the lead in setting their own goals and develop plans to meet them. They work with their schools to evaluate progress and revise goals and methods as needed. When they identify barriers preventing them from reaching their goals, they find and implement solutions, and assess the results of their choices.
- One study found that almost nine of ten students with intellectual disabilities who used the SDLMI met or exceeded their educational goals and teachers' expectations. Another study found that eighty percent of SDLMI students progressed toward their goals and more than half met or exceeded them. – Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000.

SDM IN ACTION: RUTLAND, VERMONT

- High School, VR Agency, and Waiver provider collaborated with students and families
- 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

REMEMBER THE GOAL

EVERY person with self-determination,
the “causal agent” in his or her life.

- We all need help making decisions
- People with Disabilities may need more or different help but have the **SAME** rights
- People with Disabilities having “the same opportunities for success and security as their nondisabled peers” – Gustin & Martinis, 2016

JOIN THE CONVERSATION

The National Resource Center for
Supported Decision-Making:
SupportedDecisionMaking.Org

The Burton Blatt Institute at Syracuse
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