



# SUPPORTED DECISION MAKING IN SPECIAL EDUCATION PROGRAMS





# What's the point of Special Education programs? What should they do for students with disabilities?

There are many answers to these questions. For example, Special Education programs should increase inclusion and provide a Free Appropriate Public Education. But the best answer comes from the Individuals with Disabilities Education Act (IDEA), the law that created the Special Education system. IDEA says Special Education programs must give students "services designed to meet their unique needs and prepare them for further education, employment, and independent living." 1

That means Special Education programs must help students get what they need to lead their best, most independent lives. That's especially important for students with disabilities that make it harder for them to learn, work, and live independently – those at risk of guardianship or conservatorship.

Sadly, studies show that school staff often recommend that parents get guardianship or conservatorship without trying or even thinking about other options.<sup>2</sup> In some cases guardianship or conservatorship can be a good thing but in most cases guardianship and conservatorship aren't the only answer. In fact, if students with disabilities can make decisions, either independently or when they get help, guardianship and conservatorship can have a "significant negative impact on their physical and mental health."<sup>3</sup> There are other options that can help people with disabilities make their own decisions and lead their best, most independent lives.

In this brochure, we'll tell you about an option called Supported Decision Making (SDM) that may help students with disabilities learn to make their own decisions, live as independently as they can, and avoid unnecessary guardianship and conservatorship. We'll also show you ways you can request and receive SDM supports and services from Special Education programs.

#### What is Supported Decision-Making?

Supported Decision Making (SDM) is getting help when you need it, from people you choose, so you can make your own decisions<sup>4</sup>. That's how we all make decisions.

**EVERYONE.** 

Think about what you do when you have to make a tough choice, or a decision about something you don't know a lot about, or just want to "talk it out." You may ask a friend for advice or a professional for information, or you may have "go-to" people you talk to about specific things. They help you "think through" the issues and discuss the "pros and cons" of your choices. That way, you can understand your options and you choose the one that's best for you.

When you do that, you're using SDM. People give you support, so you can decide. That's it. People with disabilities use SDM, too!

SDM burst into view when a young woman named Jenny Hatch became the first person to win the right to use it instead of being put into a permanent guardianship.<sup>5</sup> Jenny showed the Judge that she had people in her life who helped her understand, make, and communicate her decisions. Because she had this support, she didn't (and still doesn't) need a guardian.

Jenny's victory was covered in national and international news, and she became known as the "rock that started the avalanche" of SDM.<sup>6</sup> Since Jenny's case, over twenty states have passed laws recognizing SDM as an option and good alternative to guardianship and conservatorship.



#### Learning to be Independent with Supported Decision-Making

When people use SDM, they make their own decisions and can have more control over their lives – more self-determination.<sup>7</sup> That's important because research shows that when people with disabilities have more self-determination, they have better lives: they are more likely to be independent, employed, active in their communities, and safer.<sup>8</sup> For example, a recent study found that people with disabilities who used SDM were more independent, self-confident, were better at making decisions, and made better decisions.<sup>9</sup>

It's the same for students with disabilities: those who have more self-determination are more likely to do better in school and more likely to live independently and work after they leave school. That's why experts have called self-determination "the ultimate goal" of Special Education programs and said that schools should help students learn to make their own decisions and advocate for themselves. So, SDM and Special Education programs should go together, to help students with disabilities have the best chance to lead their best possible lives.





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## How can I get Supported Decision-Making Services?

Ways you and your child can request and use SDM in Special Education programs.

### 1

#### **START EARLY**

We recommend that you ask the school to start working on self-determination and SDM as early as possible. It may seem strange to encourage children so young to use SDM. But this will help students form a habit of asking for and using supports. As they get older and decisions get harder, they will know to get the support they need. Students can become better, more confident decision makers and show schools and parents that they can make their own decisions and don't need a guardian or conservator.

For example, the District of Columbia Public Schools (DCPS) teaches students as young as three 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." DCPS is showing students that they should make their own decisions and should get help when they need it.

### 2

#### WORK WITH THE PLANNING AND PLACEMENT TEAM (PPT)

Each year, your child's Planning and Placement Team or PPT must review their "present levels of academic achievement and functional performance." Then, the Team must develop an IEP that prepares them "for further education, employment, and independent living."

As we said, students with more self-determination are more likely to learn, live, and work independently. So, as a member of your child's PPT, you should ask the PPT to explore your child's self-determination and ability to make decisions as it develops their Individualized Education Plan or IEP.

For example, the Virginia Department of Education's "I'm Determined" project has developed surveys and tools to help students, parents, and teachers review a student's self-determination

and decision-making abilities. You can view and download their material here: https://imdetermined.org/families/

The student's "score" on a survey should help shape their IEP. 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 to make decisions. Here is direct link to the surveys: https://imdetermined.org/all-tools/?fwp\_search\_resources=Self-determination%20checklist

## 3

#### **REQUEST AN EVALUATION**

IDEA gives parents the right to request an evaluation to determine the student's "educational needs." "<sup>16</sup> Self-determination and decision-making are "educational needs" because studies show that they are directly related to students' ability to achieve "further education, employment, and independent living," Therefore, you can ask the PPT to have a professional evaluate your child if you think they have limitations in self-determination and decision making. If the evaluation finds that they do, it should also recommend supports and services to help them improve.

We recommend that you request the evaluation by writing a letter or email to your child's PPT coordinator, Case Manager, or the school's Pupil Personnel Director. Here is sample language you may want to use or adapt: I believe [student's name] has limitations in self-determination and decision-making that are keeping [student's name] from making educational progress, including preparing [student's name] for further education, employment, and independent living. Therefore, I ask that you conduct an evaluation of [student's name] to determine if this is so and, if so, what services and supports will help [student's name] overcome those limitations.<sup>17</sup>

## 4

#### **USE THE STUDENT-LED IEP**

Education experts say that IEP teams should help students improve their "goal setting, problem solving, decision-making and self-advocacy skills ... and [provide] opportunities for students to use these skills." The Student Led IEP gives students a chance to build and practice these skills while also building their self-determination.

In the Student Led IEP, students play a lead role on their PPT and work with PPT members to develop their goals, objectives, and services. The student's responsibilities will increase as they progress in school, starting from as young an age as possible. For example, the youngest

students can introduce themselves to the PPT and say what they like to do. As they get older they can talk about their favorite subjects, what they are interested in learning more about, and what type of supports work well for them. The ultimate goal of the Student Led IEP is for the student to eventually "Chair the meeting" and "Cooperatively develop all aspects of the IEP." 19

Doesn't that sound like SDM? Isn't that a good description of people working with friends, family members, and professionals to help them make decisions?"<sup>20</sup> That's one of the benefits of the Student-Led IEP: it gives students a chance to "practice different decision-making methods in a 'safe environment.'"<sup>21</sup> That's important because research shows that students who led their PPT 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."<sup>22</sup>

## 5

#### **CREATE AND USE I STATEMENT IEP GOALS**

Students and parents can use the Student Led IEP to create goals and objectives that help them build skills and overcome their limitations. For example, if students have limitations in decision-making and self-determination, their IEPs should include goals and services designed to help them improve in those areas. Studies have found that goals focused on building self-determination can help students do better in school, at work, and in life.<sup>23</sup>

We recommend creating these goals by using I Statements. Traditional IEP goals just require students to follow rules or meet requirements. For example, a writing goal may say, "The students will use proper grammar 75% of the time." The problem with this goal is it's passive and negative: if the student doesn't use proper grammar, they fail. The student isn't encouraged to learn or do anything new or get help when they need it.

I Statement goals are active: they say what the student will do and how they will do it. For example, an I Statement writing goal might say, "Working with my teacher, I will choose subjects I'm interested in and write stories about them, using proper grammar 95% of the time."

To meet this goal, the student must choose what to write about, instead of just following grammar rules. The student must also work with their teacher to choose the subject, write the story, and use proper grammar. If the student is still having trouble with grammar, the goal encourages the student to work more, or differently, with their teacher instead of just failing. Therefore, this goal can help students improve their writing and meet education requirements while, at the same time, helping them build their self-determination and practice SDM.<sup>24</sup>

## STUDENTS CAN CREATE I STATEMENT GOALS FOR ANY SUBJECT. HERE ARE SOME EXAMPLES:

- Working with my supporters to develop my goals and objectives, I (name of the student) will attend and lead my IEP team meetings.
- With the support of my case manager, I (student name) will review assessments completed and develop needed goals and objectives as evidenced by 100% completion of the teacher created IEP writing rubric.
- Working with supporters, I (name of the student) will identify five people I trust who will help me choose education, employment, and independent living programs I am interested in.
- With the support of my case manager, I (student name) will identify the team who will assist with the selection of education, employment, and independent living programs of interest as identified by the attendance list of the person-centered process completed.
- Working with my teacher and supporters, I (name of student) will develop a study plan to help me improve in social studies by at least one letter grade.
- Working with the general education and special education teacher, I (student name) will develop a study plan to improve my social studies' grade from (present grade) to (goal grade) as evidenced by quarterly progress reports and final average.
- Working with my teacher and parents, I (name of student) will improve my spelling by identifying and playing word games that I like twice a week.
- Working with the teacher and family, I (student name) will identify and utilize various strategies of interest to improve my spelling grade from (present grade) to (goal grade) as evidenced by quarterly progress reports and final average.

#### **Transition Services**

At age 14, students with disabilities have the right to receive Transition Services to help them prepare for life after they leave school.<sup>25</sup> In a later brochure, we will show you ways to request and receive Transition Services that can help students build the skills they need to live as independently as possible. We will also discuss Connecticut's new law that requires schools to provide students and parents with information about SDM!



### We Can Help!

While some people may need guardians or conservators, we think the National Guardianship Association's position makes sense: you should at least try SDM.

Wherever you are on your SDM journey, whether you're just gathering information or you're ready to write a plan, we can answer your questions or connect you with people and organizations that may be able to help. Feel free to contact us at: <a href="mailto:SDMinfo@gmail.com">SDMinfo@gmail.com</a> or visit <a href="mailto:ctsilc.org">ctsilc.org</a>

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This brochure was adapted, with permission, from material published by the Missouri Developmental Disabilities Council. https://moddcouncil.org/

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- <sup>4</sup> Blanck, P. & Martinis, J. (2015). "The right to make choices": The national resource center for SDM. Inclusion 3(1), 24-33.
- <sup>5</sup> For information about Jenny Hatch and her case, see www.jennyhatchjusticeproject.org
- <sup>6</sup> Vargas, T. (2013, August 2). Woman with Down syndrome prevails over parents in guardianship case. The Washington Post. Available at: https://www.washingtonpost.com/local/woman-with-down-syndrome-prevails-over-parents-inguardianship-case/2013/08/02/4aec4692-fae3-11e2-9bde-7ddaa186b751 story.html
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- <sup>8</sup> Wehmeyer, M.L., & Schwartz, M, (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. Exceptional Children, 63(2), 245-255; Khemka, I., Hickson, L., & Reynolds, G. (2005). Evaluation of a decision-making curriculum designed to empower women with mental retardation to resist abuse. American Journal on Mental Retardation, 110(3), 193-204.McGloughlin (Eds.). Recent advances in special education and rehabilitation (pp. 210-224). Boston: Andover
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- <sup>14</sup> 20 U.S.C. § 1414; 34 C.F.R. 300.304.
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