

Supported Decision-Making and Self-Determination as part of the IDEA Transition Planning Process



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Overview

- IDEA and notice of transfer or rights
- Key differences between guardianship and Supported Decision-Making
- Recent Changes to the Maine Probate Code
- Supported Decision-Making Handbook
- How does this relate to the transition planning process under the IDEA?





Maine Unified Special Education Regulations (MUSER) IX.3.G.

INDIVIDUALIZED EDUCATION PROGRAM (IEP)

11. Age of Majority

If the child will turn 17 during the course of this IEP period, child and parent(s) have been informed of the transfer of rights at the age of majority

(18). IDEA 300.320(c)-Transfer of rights at age of majority. YES Date: N/A

Transfer of Rights

The Individuals with Disabilities Education Act (IDEA) requires that schools provide notice of the transfer of rights “not later than one year before” a student reached the age of majority.

At the age of majority (age 18 in Maine), the following rights transfer to the student under the IDEA:

- receive notices and to attend IEP meetings
- consent to reevaluations
- consent to changes in placement
- request a mediation or a due process hearing to resolve a dispute about an evaluation, identification, eligibility, IEP, placement, or any other aspects of the entitlement of free and appropriate public education.

What does the research say?

- Neither parents nor educators are generally knowledgeable about what guardianship entails or what alternatives to guardianship may exist.
- When educators and families discuss the transfer of IDEA rights, guardianship remains the most frequently discussed option. Alternatives like supporting decision making are the least frequently discussed.

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What does the research say?

- In order to achieve the IDEA's goals for transition, schools must take into account whether students will likely need supports around making certain decisions.
- “When families and educators expect and plan for interdependence during transition, students with disabilities have many opportunities to partake in making decisions with support that leads to growth and maturity.”

See: MacLeod, Kate, *“I should have Big Dreams”*: A Qualitative Case Study on Alternatives to Guardianship. Education and Training in Autism and Developmental Disabilities, 2017, 52(2), 194-207.

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What is Guardianship?

- Guardianship is the legal process by which the right and power to make decisions and enter into legal relationships is taken away from one person because of his/her alleged capacity, and given to another, the Guardian.
- Full guardianship removes all legal rights, including the right to decide about health, money, education, work, where to live, with whom to associate, marriage, and making contracts of any kind.
- Historically, guardianship in Maine has been awarded on basis of diagnosis, “best interests,” and alleged inability to make “responsible decisions.”



What is Supported Decision-Making?

Supported Decision-Making (SDM) is “a series of relationships, practices, arrangements, and agreements of more or less formality and intensity designed to assist an individual with a disability to make and communicate to others decisions about the individual’s life.”

- Robert Dinerstein



Maine's New Guardianship Law

- Effective **SEPTEMBER 1, 2019**
- Defines Supported Decision-Making
- Explicitly requires consideration of less restrictive alternatives (including SDM!) prior to awarding guardianship



Supported Decision-Making in Maine's New Probate Code

32. **Supported decision making.** “Supported decision making” means assistance from one or more persons of an individual’s choosing:
- A. In understanding the nature and consequences of potential personal and financial decisions that enables the individual to make the decisions; and
 - B. When consistent with the individual’s wishes, in communicating a decision once it is made

18-C M.R.S. § 5-102(32) (2019 Probate Code)



Standard of Guardianship

Former Probate Code:	Current Probate Code:
<p>The individual is an "incapacitated person":</p> <p>"Lacks sufficient understanding or capacity to make or communicate responsible decisions concerning his person"</p>	<p>The individual "lacks the ability to meet essential requirements for physical health, safety or self-care because" he/she:</p> <p>"is unable to receive and evaluate information or make or communicate decisions, even with appropriate supportive services, technological assistance or supported decision making that provides adequate protection for the respondent"</p> <p>"identified needs cannot be met by a protective arrangement instead of guardianship or other less restrictive alternatives; . . . that provide adequate protection for the respondent"</p>

Less Restrictive Alternative in Maine's New Probate Code

- "Less restrictive alternative" means an approach to meeting an individual's needs that restricts fewer rights than would the appointment of a guardian or conservator.
- "Less restrictive alternative" includes **supported decision making**, appropriate technological assistance, appointment of an agent by the individual, including appointment under a power of attorney for health care or power of attorney for finances, or appointment of a representative payee.

SDM/Less Restrictive Alternatives Must Be Considered During Key Stages of Court Process

- Petition
- Visitor's Report
- Judge's Order
- Annual Report



Implementing SDM

*Supported Decision-Making: A User's Guide
for People with Disabilities and Their
Supporters*

www.supportmydecision.org



Which Types of Decisions Need Support

WHEN DO I NEED SUPPORT?
There are many areas of life where a person may need help with making decisions. Some examples are below:

<p>FINANCES</p> <p>Do you need help understanding your bills (cell phone, electricity, rent, internet, etc.)?</p> <p>Do you need help with buying items (understanding which deals are good, which products are going to work best for your needs, knowing if you can afford the items)?</p> <p>Do you need help setting up a checking or savings account?</p>	<p>HEALTHCARE</p> <p>Do you need help scheduling and remembering doctor's appointments?</p> <p>Do you know what medicines you take, how to find out the dosage amount, and understanding what the side effects may be?</p> <p>Do you understand how your health care costs are covered (Medicaid, private insurance) and what your copays are?</p>
<p>EDUCATION</p> <p>Do you know what accommodations are in your IEP at school?</p> <p>Do you need help deciding what college you should attend?</p>	<p>WORK</p> <p>Do you know what accommodations you need at work and how to request them?</p> <p>Do you need help understanding your employee handbook or work policies?</p>
<p>LIFE PLAN</p> <p>Do you know where you want to live and what you should know before choosing a home?</p> <p>Do you know how to find transportation to places in your community?</p> <p>Do you know the difference between healthy and unhealthy relationships?</p> <p>Do you know how to plan for an emergency?</p>	<p>LEGAL MATTERS</p> <p>Do you need help understanding your rights?</p> <p>Do you know what to do if you think someone is violating your rights?</p>

These are just some examples. You may think of other times you need support in these areas, or you may think of new areas not listed above.

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What Kind of Support

- Gathering necessary information
- Educating the Decision-Maker (DM) about that information
- Helping to identify possibilities and alternatives
- Aiding the DM in weighing choices and understanding consequences
- Communicating the DM's decision to others
- Helping to implement the DM's decision

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Choosing Supporters

- The DM chooses who to use as supporters
- Supporters never substitute their own choices for those of the DM
- Can be family members, friends, neighbors, service coordinators, church members, professionals in the community
- DM can assign certain supporters to certain types of decisions and not others



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SDM Agreements

- The document on which an individual with a disability identifies decision supporter(s) and areas of decision-making requiring assistance, as well as the type of assistance being sought.
- Examples of areas of decision-making that may require support:
 - Health
 - Finances
 - Living arrangements
 - Relationships
 - Education
 - Employment

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Transition under the IDEA

Transition planning must begin “**no later than the 9th grade**, or earlier, if determined appropriate by the IEP Team...”

The **student must be invited to attend** IEP meetings where transition will be discussed and if “the child does not attend the IEP Team meeting, the public agency must take other steps to **ensure that the child's preferences and interests are considered**”

Transition under the IDEA

Transition under the IDEA is a “**results-oriented process**, that is focused on improving the academic and functional achievement of the child with a disability **to facilitate the child's movement from school to post-school activities**, including postsecondary education, vocational education, integrated employment (including supported employment); continuing and adult education, adult services, independent living, or community participation.”

Transition planning must be “based on the individual child's needs, **taking into account the child's strengths, preferences, and interests.**”

Transition under the IDEA

For transition age students, the IEP must include:

- Appropriate measurable postsecondary goals **based upon age appropriate transition assessments** related to training, education, employment, and, where appropriate, independent living skills; and
- The transition **services needed to assist the child in reaching those goals**. These can include: instruction, related services, community experiences, acquisition of daily living skills, functional vocational assessment.

“It is crucial for students with disabilities to understand and acquire the skills for self-determination during high school to ensure success in postsecondary education and the workplace. Students with strong self-advocacy skills who understand and fully participate in the development of their IEP...have better transition outcomes.”

US Department of Education, *A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities* (May 2017).

Available at:

<https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-may-2017.pdf>

And now, you will take a break to watch us try
and get technology to cooperate...

www.intelligentlives.org

This is (or is supposed to be) an excerpt from a
short film included with Intelligent Lives, titled
“Garrett Shows: I’m in Charge”.



“Teaching self-determination and exercising informed choice are **not practices limited to the most able youth with disabilities**. Schools can help foster self-determination and VR agencies can enhance career decision-making to assist youth with disabilities, including those with the most significant complex or lifelong intellectual or developmental disabilities, to achieve their desired post school goals”

US Department of Education, *A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities* (May 2017).

Available at:

<https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>

Supporting Self Determination

- Support students in establishing their own transition goals
- Ensure that students are actively involved in IEP meetings and educational planning
- Help students develop skills to direct their own learning



Supporting Self Determination

- Explicitly teach the skills that are foundational to self-determination:
 - Choice making
 - Problem solving
 - Decision making
 - Goal setting
 - Self-advocacy
 - Self-awareness
- These are all excellent areas to target with IEP goals.
- See: Wood, Wendy et al., *Promoting Student Self Determination Skills in IEP Planning*. Teaching Exceptional Children, Vol. 36, No. 3, pp 8-16 (2004).



Choice Making

All students need regular opportunities to make choices.

Do you want _____ or _____?

Which do you want to do first, _____ or _____?

What kinds of choices does the student make?

How does the student indicate her choices?

Does the Student use experience from past choices to make better future choices?

Sample Goal:

By October 2020, the Student will select between 2 leisure options using an eye gaze with less than two prompts.

Problem Solving / Decision Making

Teaching decision making involves teaching students to:

- identify a problem/decision
- generate possible choices/solutions
- identify possible consequences (+ or -)
- examine the relative probability and importance of the consequences

When empowering students to make decisions and solve problems, consider also helping them identify who might help them with certain types of decisions.

Sample Goal: Given exposure to at least five different job types, I will select which type of work experience I want for summer employment and express why.

Goal Setting and Attainment

Teaching students to set and work toward a goal involves teaching and providing opportunities to:

- identify a goal
- outline steps to reach the goal
- identify current status in relation to the goal
- develop a plan
- evaluate progress

Sample Goal: By March 2020, I will make a presentation to my class about my progress toward the goal of renting my own apartment and living independently after graduation from high school.

Self-advocacy and self-awareness

Involve students in all decisions that impact them

Teach students about:

- their rights and responsibilities
- when and how to ask for help
- how to communicate effectively
- how to work as part of a team.

Sample Goals:

By January 2020, I will develop a personal list of learning accommodations that work best for me and will share this information individually with my teachers.

*With the support of my teachers and parents, I will lead my next annual IEP Team meeting on _____.

www.supportmydecision.org

“Through a presumption of competence, we can begin to engineer a paradigm shift, committed to recognizing the potential of all individuals to achieve independence and provide them with both access to and legitimization of their capacity to make decisions about their own lives. By focusing on the purpose and language of the IDEA, educational institutions can develop positive constructions of disability in which individuals are included and valued within their communities, and empowered to practice decision making, with or without assistance.”

See: Rood, Carrie, et al., *Presumption of Incompetence: The Systematic Assignment of Guardianship Within the Transition Process*. Research and Practice for Persons with Severe Disabilities, 2015, 39(4), 319-328.

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Questions?

Please don't hesitate to reach out to any of the advocates at Disability Rights Maine to learn more about Supported Decision-Making.

Disability Rights Maine

(207) 626-2774

1-800-432-7825

