

Understanding Informed Consent in Special Education

Oregon Department of Education
Office of Enhancing Student Opportunities

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This document is a working draft and does not constitute official agency guidance. It is being shared for feedback purposes to refine content before final release.

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Introduction

Navigating the transition to adulthood is a pivotal moment for disabled students and students experiencing disability. As rights transfer at the Age of Majority (18), schools face a complex ethical and legal responsibility: to honor the student’s autonomy while ensuring they have the support necessary to make high-stakes educational decisions.

This document explores the concept of Informed Consent, the bedrock principle that allows a student (or their surrogate) to meaningfully agree to an educational program. Informed consent is not a one-time signature; it is a process rooted in respect, accessibility, and genuine partnership.

Foundational Principles

This guidance is rooted in the following core values:

1. Presumption of Competence

We begin with the unshakeable assumption that all students are capable of making decisions about their lives unless specific, documented evidence demonstrates otherwise. Capacity is not something a student must “earn”; it is a right they possess. The burden of proof lies on demonstrating inability, not ability.

This presumption applies equally to students with intellectual disabilities, significant support needs, non-traditional communication methods, and episodic mental health conditions. A student’s disability or diagnosis is never sufficient grounds to assume incapacity.

2. Dignity of Risk

Overprotection can inhibit growth. All young adults have the right to take reasonable risks, make decisions others consider “unwise,” and learn from natural consequences. A decision that professionals disagree with is not evidence of incapacity.

A person’s expressed joy, comfort, or distress — even when expressed non-verbally — are valid data about their preferences and should guide our support, not our determination of capacity.

3. Supported Decision-Making

Decision-making rarely happens in a vacuum. We all rely on advice, counsel, and support from people we trust. Recognizing that a student relies on trusted adults to help interpret information, explore options, or communicate choices does not mean they lack capacity. It means they are using Supported Decision-Making, a recognized less restrictive alternative to guardianship.

Supported Decision-Making enhances autonomy rather than replacing it. The student remains the decision-maker; they are simply supported in the process.

4. Relational Ethics

Informed consent is fundamentally relational. It emerges from genuine dialogue, not from a unilateral pronouncement by professionals. The student, family, and professionals all bring essential knowledge. The student is the expert on their own life, preferences, and values. Their knowledge of self cannot be replaced by assessment scores or professional judgment.

5. Least Restrictive Alternative

Decisions about educational authority should use the least restrictive means necessary to ensure the student can provide informed consent. This principle creates a clear hierarchy: Supported Decision-Making first, then Conditional Surrogate (if capacity fluctuates), then Full Surrogate (if capacity is continuously impaired). Guardianship is an option that families can choose to pursue, but is not required for school districts to ensure that every adult student’s IEP is being implemented with informed consent.

Part 1: The Three Pillars of Informed Consent

Informed consent requires that three components are present simultaneously: Information, Voluntariness, and Capacity.

Pillar 1: Information Provided in Understandable Language

A student cannot consent to something they have not been given the chance to understand in a truly accessible way.

What Must Be Disclosed

- **The nature of the action:** What is being proposed? Use plain, concrete language. Say “You will take reading classes in a different room” rather than “You will receive pull-out reading services.”
- **The benefits:** What good outcomes might result?
- **The risks:** What could go wrong? This is often overlooked but is ethically essential.
- **The alternatives:** What other options exist? What would happen if we don’t do this?
- **Honest uncertainty:** It is acceptable — even necessary — to say “We don’t know for sure what will happen.”

Accessibility as a Civil Right

Information must be provided in ways that are genuinely accessible. This is not a courtesy; it is a legal and ethical obligation. When information is dense, inaccessible, or presented only in complex formats, we risk excluding families and students with less social capital.

- **Native language and preferred mode of communication:** Documented in the Capacity Form, this must be honored consistently.
- **Plain language:** Research shows many special education procedural documents are written at a college reading level. Aim for 5th - 8th grade reading level. Avoid jargon. Use visual supports, simplified sentences, and concrete examples.
- **Processing time:** Many students need more time to absorb information. Do not rush. Pause frequently. Ask the student to explain back what they understood.

Pillar 2: Voluntariness (Freedom from Coercion)

Consent is only valid if given freely, without pressure or threat.

Recognizing Coercion

Coercion can be explicit (“If you don’t agree, we’ll call child protective services”) or subtle:

- Presenting an option as the “responsible” or “standard” next step
- Making families feel that disagreement will result in worse outcomes for their child
- Implying that refusing a service will mean the child is unsupported
- Using authority and professional status to pressure agreement

Power Dynamics

Be aware that students and families often feel profound power imbalances with schools. They may agree to things they do not actually want because they fear consequences. Explicitly give permission to disagree. Say: “You have the absolute right to say no. Saying no will not affect any other services your child receives or how we treat your child.”

The Right to Revoke

A person must understand they can revoke consent at any time. If a student agrees to a placement and later wants to reconsider, that is their right. Revocation should never result in retaliation or loss of other services.

Pillar 3: Capacity (Functional and Contextual)

Capacity is not a medical diagnosis or a static trait. It is the functional ability to participate meaningfully in a specific educational decision at a specific time, with appropriate supports and accommodations.

The Four Domains of Capacity Assessment

The *Determining Adult Student Capacity Form* assesses capacity across four specific domains. Understanding these domains helps teams move away from global impressions (“She can’t understand anything”) toward specific, observable evidence (“She can understand information about class choices if given extra time and visual aids”).

A. Understanding Educational Information.

Can the student grasp the essential information about the decision at hand?

- Does the student understand the purpose of the IEP or the specific decision being made?
- Can they recognize their own educational strengths and needs?
- Can they retain the information long enough to make a choice?
- Can they understand the consequences (in simple terms) of different choices?

Important note: Understanding does not need to be perfect, comprehensive, or technical. A student who understands “I will have reading help” may not need to understand the specific phonics approach. What matters is understanding the essential gist of the decision.

B. Communication of Preferences and Decisions.

Can the student express what they want or don’t want?

- Can the student express a consistent choice?
- This can be verbal, written, via AAC device, through pointing, consistent behavioral indicators, or other communication methods recognized by people who know them well.
- Can the student say “yes” or “no” to a proposal?
- Can the student ask questions or request clarification?

Critical insight: Inconsistency due to anxiety, pressure, fatigue, or changing circumstances does not necessarily mean incapacity. Many people’s preferences fluctuate depending on context and mood. What matters is whether the student can communicate a preference that is stable enough to guide decision-making.

Non-verbal communication counts: A student who consistently points to “yes” or consistently looks away when distressed is communicating. Honor that communication.

C. Evaluation of Options.

Can the student weigh options and consider consequences?

- Can the student identify pros and cons of different choices, even in simple terms?

- Can they connect a decision to their personal goals? (e.g., “I want to do that class because it helps me learn to work”)
- Can they identify potential consequences, even if they choose to proceed anyway?
- Can they consider input from supporters while still making their own choice?
- Can they adjust their thinking when presented with new information?

Key principle: The ability to reason does not mean the student must reach the same conclusion professionals would reach. A student who says “I understand it might be hard, but I still want to try it” is demonstrating reasoning capacity. The fact that their judgment differs from the professional team’s judgment is not evidence of incapacity.

D. Real-World Application.

Does the student demonstrate decision-making in actual daily life?

- Does the student make choices and decisions in contexts outside the IEP meeting?
- Do they apply learning from past experiences to new decisions?
- Can they identify when they need help and ask for it?
- Do they advocate for their own needs?
- Do their choices reflect awareness of safety?

Critical insight: A student who knows when to ask for help is demonstrating genuine capacity wisdom. We must not misinterpret help-seeking as dependence; it is intelligent self-advocacy.

Part 2: Assessing Capacity: Static vs. Fluctuating

The assessment process differs depending on whether a student’s capacity is stable or fluctuates over time. This distinction is crucial for determining the appropriate level of support.

Static Capacity Assessment

Use this approach when assessing a student whose capacity appears relatively stable or consistently impaired.

Use the *Determining Adult Student Capacity Form* to:

- Document evidence across all four domains
- Note which supplementary aids and services were tried and their effectiveness
- Make a determination: Does the student have capacity to provide informed consent?
 - If YES, then no surrogate is needed. Continue with Supported Decision-Making and accommodations as appropriate.
 - If NO, the student may need a Surrogate Parent (documented under OAR 581-015-2325(2)) to represent them in educational decision-making.

Fluctuating Capacity Assessment

Use this approach when a student has periods of capacity alternating with periods of impaired capacity.

Key question to ask

Are there identifiable circumstances, patterns, or conditions under which this student's capacity is predictably impaired?

Examples may include:

- Acute psychiatric episodes (hospitalization, severe depression, psychosis)
- Post-seizure states or other medical events affecting cognition
- Trauma-related dissociation following specific triggers
- Autistic burnout or sensory overwhelm episodes
- Acute grief or major life disruptions

If YES, the student may be a candidate for a Conditional Surrogate.

When Conditional Surrogate May Be Appropriate

A Conditional Surrogate is appropriate when ALL of the following are true:

1. The student has reached age 18 and has not had rights transferred to a court-appointed guardian.
2. The student experiences documented patterns of fluctuating capacity (not simply bad days or minor challenges).
3. The student can provide informed consent to the conditional arrangement during a period of capacity.
4. Specific, observable, predictable activation criteria have been identified and documented.
5. Clear deactivation criteria have been documented so authority is restored when the period of impaired capacity ends.

Important distinction: A Conditional Surrogate's authority activates only when specific criteria are met and deactivates when the student recovers capacity or the triggering circumstances resolve. Between activations, the student retains full decision-making authority.

Part 3: The Process of Determining Capacity

Step 1: Start with Supported Decision-Making

Before considering any surrogate arrangement, document your efforts to support the student in making their own decisions.

Examples of Supported Decision-Making strategies:

- Providing extra processing time
- Using visual aids, simplified language, or graphic organizers
- Breaking complex decisions into smaller steps
- Allowing the student to bring trusted supporters to meetings

- Scheduling meetings at times when the student is typically more alert
- Allowing the student to prepare in advance
- Checking understanding frequently and asking the student to explain back
- Connecting decisions to the student's known values and goals

Document:

- Which strategies were tried
- How long they were used
- How effective they were
- Evidence of the student's growing or consistent participation

Step 2: Gather Evidence

Collect information from multiple sources:

- **The student's own perspective:** What does the student say about their abilities? What do they want? How do they experience their own decision-making?
- **Observation of real-world functioning:** Look for evidence of decision-making in authentic contexts (choosing food, navigating campus, requesting help), not just in formal meetings
- **Family/caregiver input:** People who know the student best often have crucial information about patterns and capacities
- **Transition assessment data:** Age-appropriate transition assessments document preferences, interests, and decision-making skills
- **Educational records:** IEP history, progress on self-advocacy goals, communication logs
- **Medical/mental health information:** Any relevant information about fluctuating conditions or episodic challenges (with appropriate confidentiality protections)

Critical principle: Do not rely on disability diagnosis alone. An intellectual disability diagnosis does not tell you whether this student can understand an IEP. A psychiatric diagnosis does not tell you whether this student can make educational decisions right now.

Step 3: Use the Four Domains

Assess the student's functioning across the four domains:

1. **Understanding:** Can they grasp the essential information?
2. **Communication:** Can they express a preference?
3. **Evaluation:** Can they weigh options and consider consequences?
4. **Real-World Application:** Do they demonstrate decision-making in actual life?

For each domain, look for:

- Specific, observable evidence (not general impressions)
- Evidence of what the student CAN do with supports
- Information about which supports are most effective
- Patterns over time (is the student improving? consistent? declining?)

Step 4: Make a Determination

Based on all available evidence, the IEP team determines:

1. Does this student have capacity to provide informed consent about their educational program?
 - a. If YES (with or without supports): Document this. No surrogate is needed. Identify which supports help the student participate most fully, and ensure those supports are consistently provided.
 - b. If NO, but capacity fluctuates: Consider whether a Conditional Surrogate is appropriate (see Part 2 and Conditional Surrogate Core Guidance).
 - c. If NO, and capacity is continuously impaired: Consider whether a Surrogate Parent is needed (see Part 4).
2. Document the basis for the determination:
 - a. What specific evidence led to this conclusion?
 - b. What were the alternative interpretations considered?
 - c. What is the team's reasoning?

Part 4: When Surrogate Appointment May Be Necessary

Surrogate Parent (Ongoing Authority)

If the IEP team determines the student continuously lacks capacity to provide informed consent, even with maximum supports and accommodations, a Surrogate Parent may be appointed.

Requirements (OAR 581-015-2325(2)):

- The student has reached age 18
- The student does not have a court-appointed guardian
- The IEP team has documented that the student cannot provide informed consent even with supplementary aids and services

Priority for appointment:

- **First:** The student's parent (unless unwilling or unavailable)
- **Second:** Another qualified adult who has positive relationship with student, understands surrogate responsibilities, and has knowledge to represent the student's interests

Conditional Surrogate (Fluctuating Authority)

If the student has fluctuating capacity, a Conditional Surrogate may be more appropriate. See Part 2 and the Conditional Surrogate Core Guidance for detailed guidance.

Part 5: Alternatives to Surrogate Appointment

Before appointing any surrogate, fully explore less restrictive alternatives:

1. Supported Decision-Making – The First Choice

The student retains full rights and makes their own decisions with support from people they choose.

How it works:

- The student identifies trusted supporters (family, friends, teachers, mentors)
- These supporters help the student understand options, explore pros/cons, and communicate their choice
- The student makes the final decision

Advantages:

- Preserves the student's right to make decisions
- Builds decision-making skills through practice
- Flexible and easily adjusted
- Can be informal or formalized through a written agreement

When to use:

Use supported decision-making for most students, including those with significant intellectual disabilities, autism, mental health conditions, and other disabilities. Supported decision-making can work for a very wide range of students.

For students who struggle with decision-making, try:

- Providing information in multiple formats (written, visual, spoken, demonstrated)
- Breaking complex decisions into smaller decisions over time
- Using decision-making frameworks or visual organizers
- Meeting multiple times to allow processing time
- Connecting decisions to the student's known values and goals
- Allowing extra time between meetings so the student can think and consult supporters
- Using assistive technology or communication aids
- Scheduling meetings when the student is typically most alert

Key principle: Many students can make decisions with these supports who would be deemed "incapable" without them.

Documentation:

Document the supporters identified, the strategies used, and how the student participates in decisions.

2. Educational Delegation Agreement (Power of Attorney for Educational Decisions)

A student with capacity can voluntarily delegate educational decision-making to a parent or other agent.

How it works:

- The student, with capacity, signs a delegation agreement
- The designated agent makes educational decisions on the student's behalf
- The arrangement can be modified or revoked by the student at any time

When to use:

An adult student who can provide informed consent to such an arrangement, but prefers not to make educational decisions independently, would make this choice. The decision to pursue educational delegation is a personal choice of the individual and should not be influenced by others.

3. Informal Support

The student makes decisions but invites supporters to IEP meetings, consults with them, and considers their advice.

Advantages:

- Maximally preserves student autonomy
- Allows family involvement without formal arrangements
- Simple to implement

Part 6: Red Flags (What NOT to Do)

Do NOT Determine Incapacity Because:

- **The student makes a decision the team disagrees with.** A student with capacity has the right to make decisions others consider unwise. Exercising this right is not evidence of incapacity.
- **The student refuses to participate or is uncooperative.** Unwillingness to engage, resistance, or refusal to comply with recommendations does not equal inability to provide informed consent. These are behavioral or motivational issues, not capacity issues.
- **The student has a disability diagnosis or classification.** Having autism, intellectual disability, psychiatric diagnosis, or significant support needs does not automatically mean the student lacks capacity for educational decisions. Capacity must be assessed individually and specifically.
- **The student is on an involuntary psychiatric hold.** An involuntary hold addresses danger and safety concerns; it does not automatically mean the student cannot make educational decisions. These are separate legal determinations.
- **The student makes poor choices.** Judgment that differs from professional judgment is not incapacity. The “dignity of risk” includes the right to make mistakes.
- **Removing decision-making authority would be more convenient for staff.** The arrangement exists to protect the student's rights and autonomy, not to streamline IEP processes.

Do NOT Base Capacity Determination on:

- “When the student is stressed or upset”
- “When the student refuses medication”
- “When the student does not comply with treatment”
- “When the student exhibits challenging behaviors”
- “When the student had a bad day”
- “When the student is depressed” (without connection to specific inability to understand, communicate, reason, or apply decisions)

Capacity determinations must be tied to documented inability to perform the four functions: understanding, communicating, evaluating, and real-world application.

Do NOT Use Surrogate Authority to:

- Remove the student from IEP meetings
- Prevent the student from communicating their preferences
- Override the student’s expressed wishes without documentation that the student cannot understand or communicate them
- Make decisions based on the surrogate’s judgment of what is “best” rather than the student’s known preferences and values
- Keep a student isolated from decision-making any more than absolutely necessary

Summary: A Quick Reference for Practitioners

Before Any Determination:

- ☑ **Presume Competence:** Start with the assumption the student can decide.
- ☑ **Use Supported Decision-Making First:** Document attempts to support the student in making their own decisions.
- ☑ **Gather Evidence:** Collect information from multiple sources about the student’s actual functioning.
- ☑ **Provide Maximum Accommodations:** Use visual aids, extra time, plain language, trusted supporters—whatever helps the student participate fully.

When Making a Determination:

- ☑ **Use the Four Domains:** Assess capacity based on Understanding, Communication, Evaluation, and Real-World Application.
- ☑ **Look for Specific Evidence:** Document observable evidence, not general impressions.
- ☑ **Distinguish Static from Fluctuating:** Is capacity continuously impaired, or does it fluctuate?
- ☑ **Use the Appropriate Tool:**
 - Determining Adult Student Capacity Form for overall capacity assessment
 - Conditional Surrogate Core Guidance and Sample Agreement for fluctuating capacity

After a Determination:

- ☑ **Document Everything:** The basis for the determination, evidence considered, supports tried, and the team's reasoning.
- ☑ **Inform the Student:** Ensure the student receives notice of the determination in accessible language.
- ☑ **Respect Challenge Rights:** The student has the right to challenge the determination.
- ☑ **Review Regularly:** Capacity can change. Annual review is required; more frequent review may be appropriate.

Closing Principle: Humility and Respect

The determination of whether someone has capacity to make decisions about their own life is one of the most consequential determinations a school team can make. It affects their autonomy, dignity, and future.

Approach this work with:

- ☑ **Humility:** Recognize the limits of what tests and observations can tell us. Some students' capacities cannot be neatly categorized. Trust the student and their supporters' own knowledge.
- ☑ **Respect:** Presume the student is trying to live a full, self-directed life according to their own values. Honor their expressed preferences, even when expressed non-verbally or unconventionally.
- ☑ **Caution:** Removing someone's rights, even temporarily or conditionally, is a serious action. The bar for doing so should be high. The burden of proof should lie on demonstrating genuine incapacity, not on the student proving capacity.
- ☑ **Partnership:** The IEP team exists to support the student, not to control them. Parents, students, and professionals all bring essential knowledge. Working together results in the most favorable outcomes.