

Assent as a Human Right

Organization for Autism Research

Noor Syed

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Learning Outcomes

- Participants will define assent, assent withdrawal, and dissent, and differentiate them from consent and compliance.
- Participants will develop individualized assent and dissent protocols.
- Participants will describe ways to modify environments to support learner autonomy across varying language needs.
- Participants will explain how to incorporate community-informed practices to develop interdisciplinary methods that support autonomy and assent.

Agenda



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Foundations of Assent

Recognizing Assent

Supporting Meaningful Participation

Strategic Decision-Making

Looking ahead



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What is assent?

Term	Definition	References
Informed consent	Legally valid and informed permission to participate in services, research, or other activities. Consent requires adequate information, understanding, and voluntary agreement , and may be provided by the individual or a legally authorized decision-maker. Consent is an ongoing process and may be withdrawn.	Breaux & Smith (2023); Flowers & Dawes (2023); BACB Ethics Code; Physicians for Human Rights (2024)
Assent	An individual's affirmative agreement or willingness to participate, communicated through vocal and/or nonvocal behavior. Assent is individualized, ongoing, and may be expressed through words, actions, approach behaviors, engagement, or other communication forms. Mere absence of objection does not necessarily indicate assent.	Breaux & Smith (2023); BACB Ethics Code; Lestremau Allen et al. (2024); Morris et al. (2021)
Dissent	Communication indicating refusal, disagreement, discomfort, or unwillingness to participate. Dissent may be expressed vocally or nonvocally and should be interpreted in the context of the individual's communication repertoire and environment.	Breaux & Smith (2023); Flowers & Dawes (2023); Lestremau Allen et al. (2024)
Assent withdrawal	A change in behavior indicating that an individual no longer wishes to participate in an activity, interaction, or intervention after previously demonstrating assent. Assent withdrawal may occur at any point and should be viewed as an ongoing communication process rather than a one-time event.	Breaux & Smith (2023); Flowers & Dawes (2023); Allen et al. (2024)
Compliance	Engagement in a requested activity, instruction, or expectation. Compliance refers to behavior occurring in response to a request or demand and does not necessarily indicate agreement, willingness, comfort, assent, or meaningful participation.	Breaux & Smith (2023)

Note: Emphases have been added.

Key Message

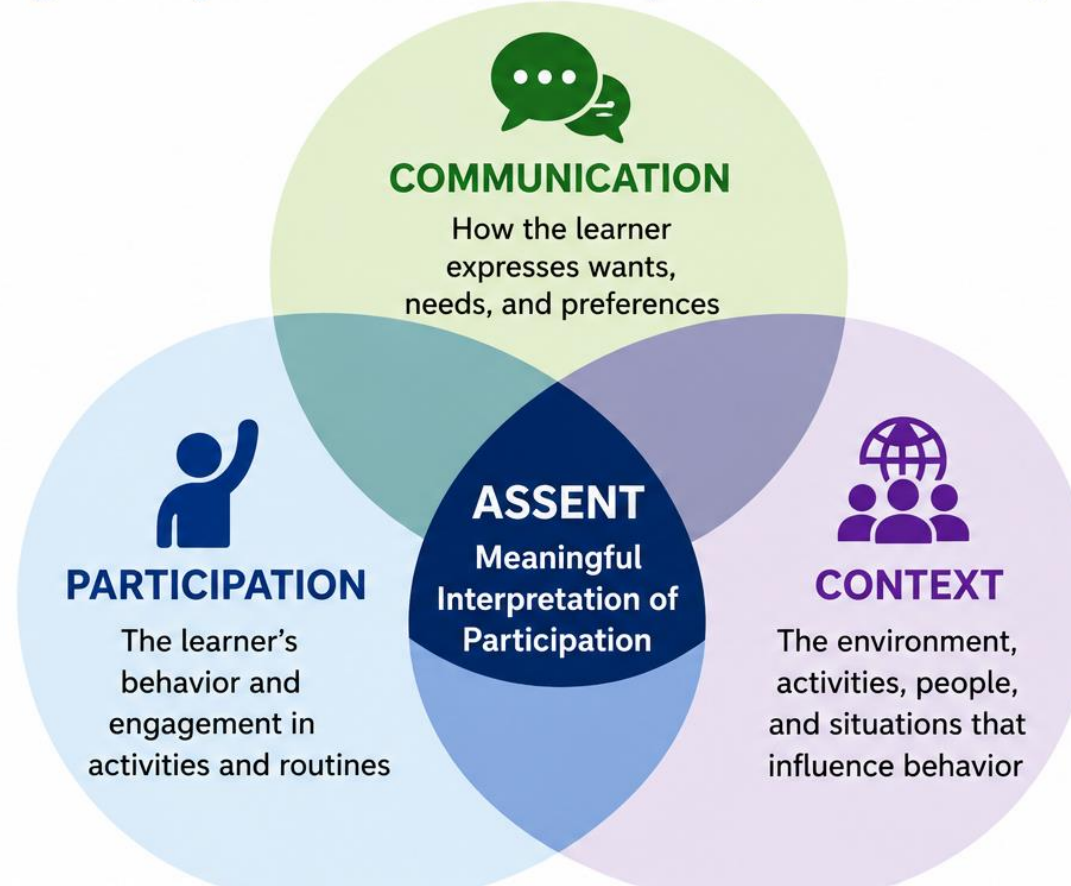
Informed consent, assent, dissent, and assent withdrawal relate to an individual's agreement or willingness to participate, whereas **compliance only refers to whether participation occurred.**

Participation alone does not necessarily indicate assent.



Assent Is a Process

Assent emerges through the interaction of participation, communication, and context.



ONGOING AND DYNAMIC: Assent is not a one-time event. It can change over time and across situations.

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Misconception 1: Compliance = Assent

Compliance $\neq$ Assent

Participation alone does NOT demonstrate willingness or agreement.

Misconception 2: Assent is only possible for speakers.

Assent and dissent can be communicated MANY WAYS- through speech, AAC, behavior, affect, body language, physiological responses, and other forms of communication.

Misconception 3: Assent means learners decide everything.

Assent involves meaningful participation in decision-making, not unlimited choice or complete control over all decisions.

Misconception 4: Once assent is obtained, it remains in effect.

Assent is **ongoing** and **can be withdrawn, changed, or fluctuate** across activities, people, and contexts.

Additional Misconceptions	Reframe
Assent means no expectations can be placed on learners.	Expectations, learning goals, and safety requirements can coexist with efforts to obtain and maintain assent.
Dissent only matters when it is explicit or disruptive.	Subtle, emerging, and context-dependent indicators of dissent warrant attention and evaluation.
Assent is solely the learner's responsibility to communicate.	Practitioners share responsibility for arranging environments, building trust, recognizing communication, and responding to assent and dissent signals.
Assent is an all-or-nothing construct.	Assent exists on a continuum and may vary across activities, conditions, and points in time.
Respecting assent means ending instruction whenever a learner objects.	Respecting assent involves understanding the function of dissent, modifying conditions, supporting regulation, and balancing autonomy, learning, and safety.

Reflection

- How do you know a learner wants to participate?
- How might your answer change if the learner does not use spoken language?

Why this Conversation Matters: Fundamental Rights

Communication Bill of Rights: Fundamental Communication Rights

- The right to refuse or reject...
- The right to express personal preferences and feelings
- The right to make choices
- The right to be treated with dignity and addressed with respect and courtesy
- The right to be addressed directly and not be spoken for or talked about in the third person while present

Thank you, Dr. Lauren Lestremou Allen!

Brady et al. (2016) <https://www.asha.org/njc>

Years Later, Many of Us Are Asking the Same Questions

1990

- How do we teach skills while preserving choice?
- How do we recognize preferences?
- How do we avoid making decisions without client input?

Bannerman et al., 1990

2026

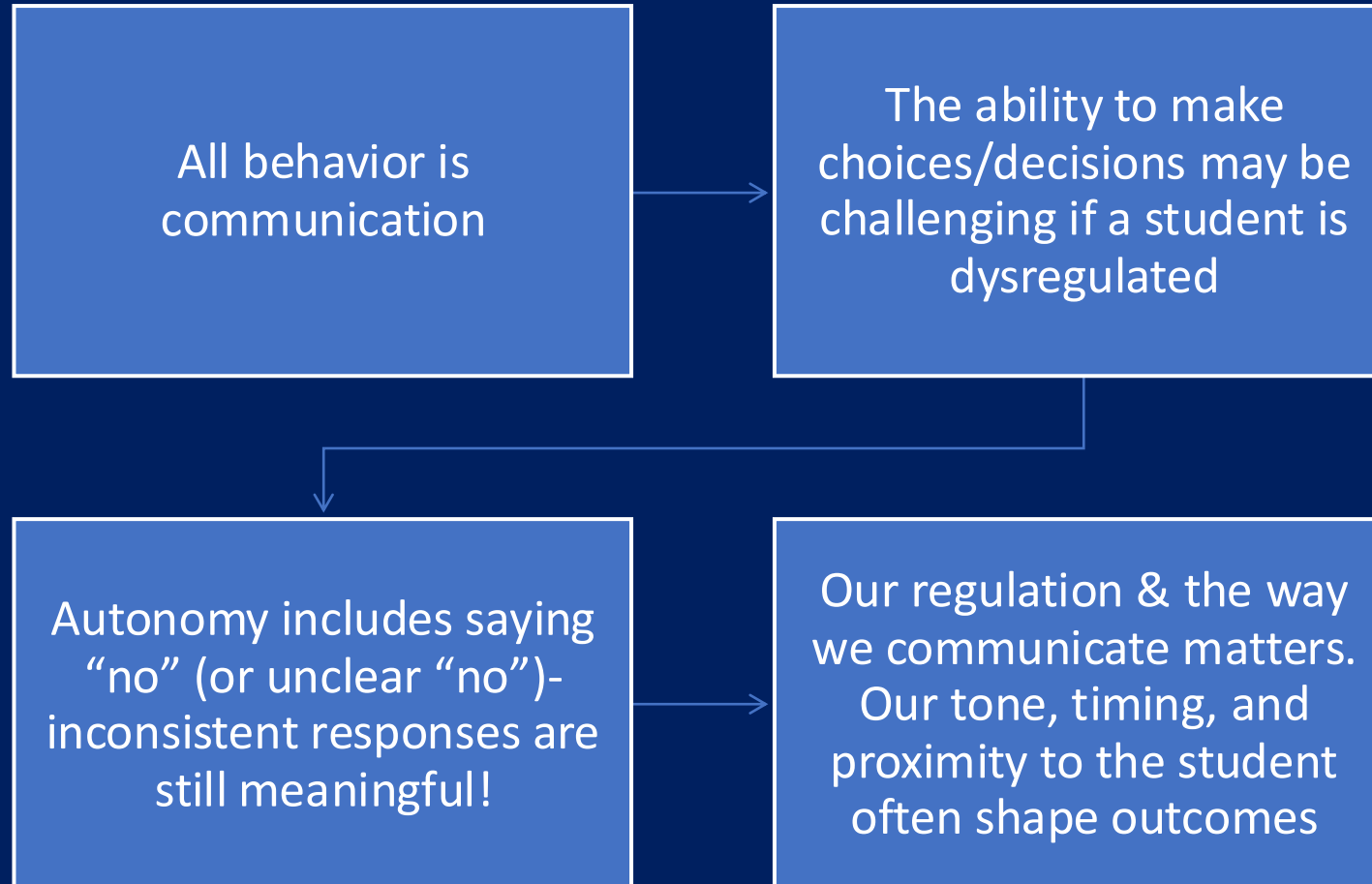
- How do we recognize assent?
- How do we respond to assent withdrawal?
- How do we build autonomy-supportive environments?
- How do we include autistic and neurodivergent voices in decision-making?

Cas & Breau, 2023; Lestremau Allen et al., 2025; Syed et al., 2025

Assent: Beyond Participation



(a few) Guiding Principles



Meet Our Learners: Case Discussions

Learner 1: Maya

Maya is a 9-year-old autistic student who communicates using spoken language. She attends a general education classroom with support services and particularly enjoys science, art, and collaborative projects. Maya frequently expresses preferences and is comfortable requesting assistance or asking questions.

Maya's class is beginning a small-group science experiment involving building and testing simple bridges. Before the activity begins, Maya:

- Walks directly to the materials table
- Asks, "Are we doing bridges today?"
- Requests to sit with a particular group
- Reviews the instruction sheet before the teacher begins

Learner 1: Maya

During the activity, Maya:

- Participates actively in planning and construction
- Asks questions about the materials
- Requests additional tape to strengthen her bridge
- Continues working after several peers have finished
- When the teacher announces that the activity is ending, Maya asks: "Can I have a few more minutes to finish testing mine?"

Discussion Questions

- What behaviors suggest assent?
- What gives us confidence in our interpretation?
- Could there be alternative explanations?
- What additional information might strengthen our confidence?

Possible Indicators of Assent

- Examples *may* include:
 - Approaching people, activities, or materials
 - Orienting toward activities
 - Initiating participation
 - Requesting continuation
 - Re-engaging after breaks
 - Expressing interest or enthusiasm
 - Requesting access to preferred activities



Key Message: Assent may be communicated in many ways and should be interpreted within the individual's unique communication repertoire.

Learner 2: Jordan

Jordan is a 12-year-old autistic learner who communicates using a combination of speech and AAC. Jordan attends a specialized educational program and has worked with the same team for several years. Staff frequently describe Jordan as "easygoing" and "compliant."

During a daily instructional session, Jordan:

- Completes all assigned tasks
- Responds accurately to most instructional demands
- Transitions between activities when prompted
- Rarely requests breaks
- Rarely comments on activities
- Rarely expresses preferences regarding materials or tasks

Staff report that Jordan:

- Almost never refuses activities
- Completes work with minimal prompting
- Typically appears calm throughout sessions

Learner 2: Jordan

During a recent team meeting, a staff member states: "Jordan always assents because he never says no."

Another team member asks: "How do we know whether Jordan enjoys these activities or wants to participate?"

Discussion Questions

- What information is missing?
- Is participation sufficient evidence of assent?
- How might we gather information about Jordan's preferences?
- What assumptions could the team be making?

Participation Does NOT Necessarily Equal Assent

- Things participation alone may not tell us:
 - Whether the learner enjoys the activity
 - Whether the learner would choose the activity
 - Whether the learner feels comfortable expressing preferences
 - Whether the learner has meaningful alternatives available
 - Whether the learner has a history of assent being recognized and honored



Key Message: Participation (“compliance”) may provide important information, but it does not necessarily indicate willingness, agreement, or assent.

Learner 3: Luis

Luis is a 7-year-old autistic learner who has participated in ABA, OT, Speech, and PT services for approximately 18 months. Luis uses spoken language and enjoys building activities, movement games, and interacting with familiar staff members. Historically, staff describe Luis as highly engaged during sessions. Over the past several weeks, Luis's team has observed changes in participation.

Previously, Luis would:

- Enter sessions enthusiastically
- Request preferred activities
- Initiate interactions with staff
- Ask to continue activities beyond scheduled times

Recently, staff have observed that Luis:

- Requests breaks more frequently
- Requires more prompting to begin activities
- Initiates less often
- Appears less engaged during tasks he previously enjoyed
- Occasionally responds with "I don't know" when asked what he would like to do

Importantly: No major increases in challenging behavior have occurred,,; Luis continues to complete most activities; Attendance remains consistent.

Learner 3: Luis

Team members disagree about what these changes mean.

- One clinician says: "I think he's withdrawing assent."
- Another says: "Maybe he's just tired or going through a phase."
- A third asks: "What information do we need before reaching conclusions?"

Discussion Questions

- What might Luis be communicating?
- What additional information would you want?
- What contextual variables should be explored?
- How might the team respond while gathering more information?

Possible Indicators of Assent



- Examples may include:
 - Turning away
 - Leaving
 - Reduced engagement
 - Material rejection
 - Escalation
 - Passive disengagement

Key Message: Look for patterns rather than isolated behaviors.

Learner 4: Amina

Amina is a 14-year-old autistic learner with extensive support needs. Amina enjoys music, sensory activities, and spending time with familiar staff and family members. Team members report that she demonstrates clear preferences but that those preferences are not always expressed through conventional forms of communication. She communicates through a combination of facial expressions, body positioning, gestures, vocalizations, and limited AAC selections.

- During a preferred music activity, Amina:
 - Walks toward the activity area
 - Smiles when materials are presented
 - Reaches toward instruments
 - Selects "more" on her AAC device
 - Re-engages following brief breaks
- During a different instructional activity later in the day, staff observe that Amina:
 - Turns her body away from materials
 - Places items on the table rather than interacting with them
 - Moves toward the classroom door
 - Produces fewer vocalizations than usual

Learner 4: Amina

- One staff member interprets these behaviors as refusal.
- Another suggests that Amina may be communicating discomfort or withdrawal of assent.
- Later, the team learns that:
 - Amina attended a loud school assembly earlier that day
 - Her AAC device battery had been low during the morning
 - Her parent reports that she slept poorly the previous night

Discussion Questions

- What might assent look like for Amina?
- What might assent withdrawal look like?
- How does context influence interpretation?
- What additional perspectives would be helpful?
- How should the team respond?

Let's Discuss Together

Examples That <u>May</u> Indicate Assent	Examples that <u>May</u> Indicate Assent Withdrawal

Each team member may observe different strengths, communication patterns, environmental influences, and priorities that contribute to a more complete understanding of the learner.



Key Message: Context is
ESSENTIAL.

- No one behavior or set of behaviors automatically indicate assent or assent withdrawal. The same behavior may have different meanings across learners and situations.
- Our goal is not to create a universal checklist, but rather to develop individualized understandings of communication patterns.

We should always ask ourselves: What might this learner be communicating in this particular situation?

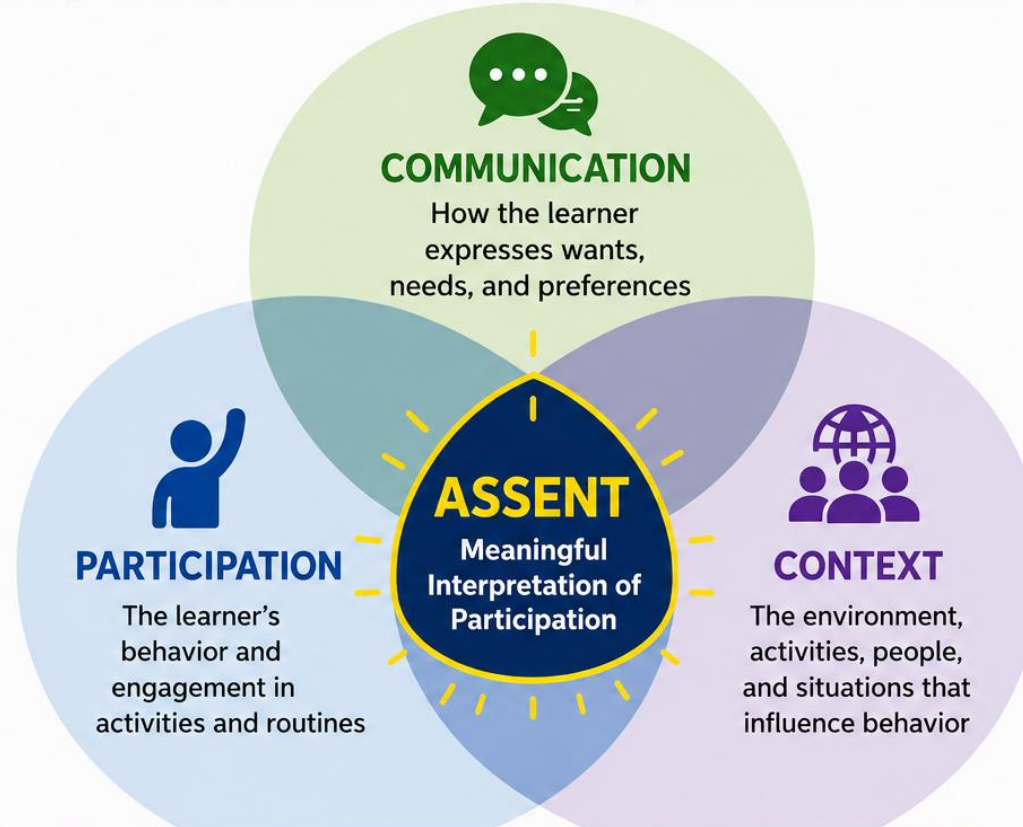
The same behavior may have different meanings depending on context. Context influences participation.

Let's revisit Amina 

What We Observe	Context	Possible Interpretation
Turns away from materials	Loud assembly, poor sleep, AAC unavailable	May be overwhelmed and need regulation support
Turns away from materials	Difficult task with limited supports	May need assistance or task modification
Turns away from materials	Preferred activity available nearby	May be expressing a preference
Turns away from materials	Pattern occurs repeatedly during one activity	May be withdrawing assent
Turns away from materials	New staff member present	May need additional rapport or predictability

Assent Is a Process

Assent emerges through the interaction of participation, communication, and context.



ONGOING AND DYNAMIC: Assent is not a one-time event. It can change over time and across situations.

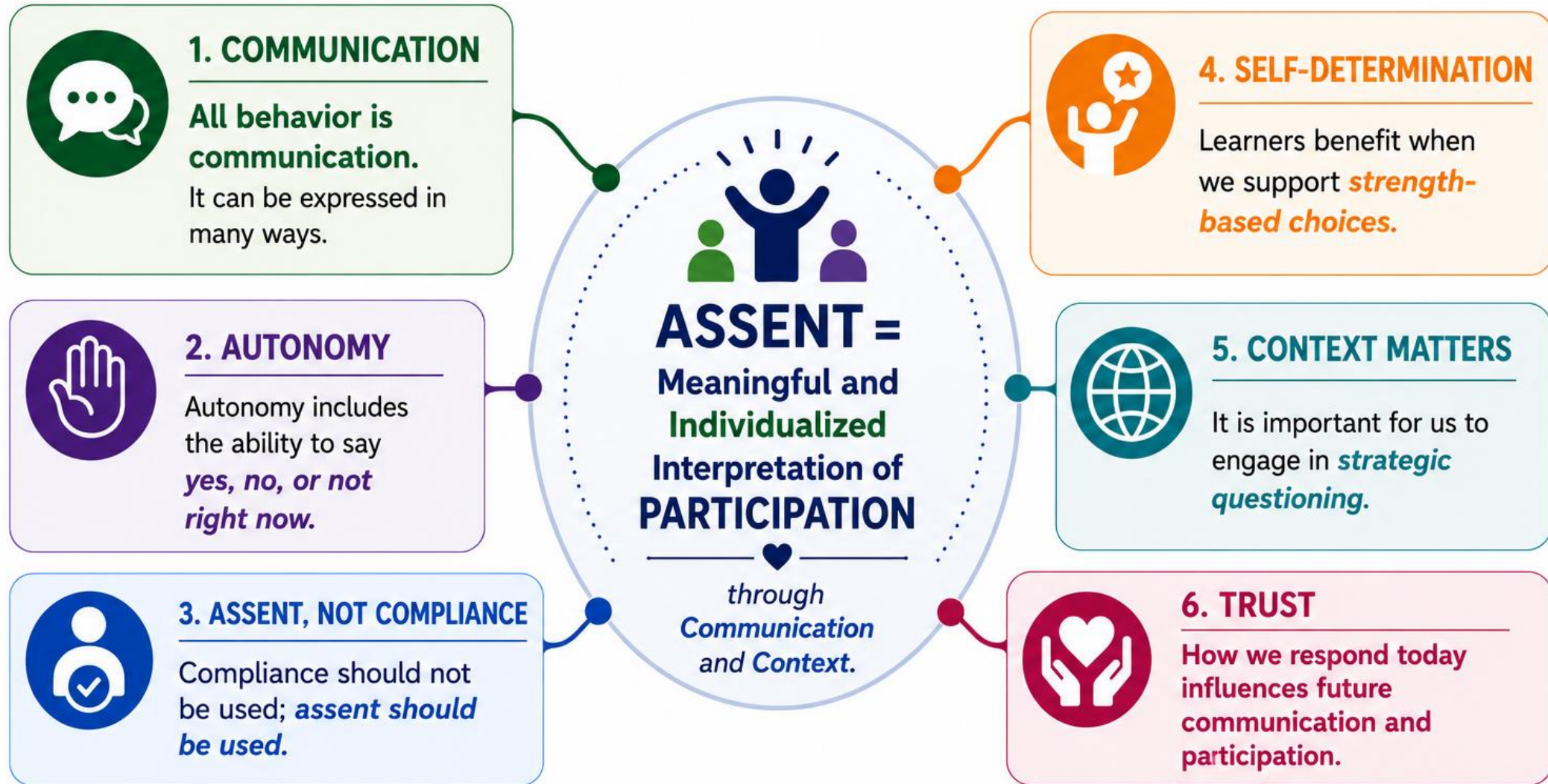
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Building Assent-Supportive Practices: Universal & Proactive Interdisciplinary Approaches

(a few more guiding principles)

Guiding Principles for Assent-Supportive Practice

➔ These principles guide how we recognize, support, and respond to meaningful participation. ⇐



We are partners with learners and their teams. Together, we create environments where every learner can communicate, participate, and be heard.



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Self-Advocacy & Meaningful, Strength-Based Choices

- Create FREQUENT opportunities for learners to influence their environment
- Expand opportunities for choice:
 - Offer meaningful choices throughout the day
 - Incorporate preferences into routines and activities
 - Recognize that choice may be communicated in many way

☐	Homework
☐	Play Outside
☐	Dinner: Lee's Choice
☐	Load dishwasher
☐	Game night: _____
☐	Shower
☐	Bedtime

With thanks to Dr. Lauren Lestremou Allen!

https://teacch.com/resources/teacch-tips/supporting_choice_making/

Self-Advocacy & Meaningful, Strength-Based Choices

- **Teach self-advocacy skills**
 - Request help
 - Request a break
 - Express preferences
 - Request modifications
 - Communicate "not right now"
- **Support Agency.** Before providing support, ask/share:
 - "Can I help?"
 - "Would you like me to show you?"
 - "I am going to help you with ____."

Ask Yourself



- Is refusal the learner's only option?
- Can the learner influence what happens next?
- Have we taught alternatives to disengagement?

- If you wanted ice cream, your ***within*** activities choice was denied.
- If you wanted to take a nap, ***between*** activities choice was denied.
- If you did not want a snack, choice to ***refuse*** was denied.
- If you wanted to leave after eating half a piece of cake, choice to ***terminate*** activity was denied.
- If you wanted to have a snack alone, your choice of ***with whom*** to participate was denied.
- If you wanted to eat your snack in the living room, your choice of ***where*** the activity occurred was denied.
- If you wanted to have a snack at a later time, your choice of ***when*** was denied.

Scenario: Person informed that it is time for a snack and can have choice of 3 cookies vs. Piece of cake

Thank you, Dr. Lauren Lestremau Allen!

Assent-Supportive Shifts

“Old instinct”	Possible shift
“They’re not listening”	“What communication might I be missing?”
“They won’t choose”	“Are they regulated enough to choose?”
“I need to prompt”	“Can I pause and observe first?”

“Old” instinct	Assent-supportive shift
Get compliance	
Prompt faster	
Fix behavior	
Control outcome	

Design environments where learners can:

Communicate in multiple ways.

Speech, AAC, gestures, visuals, movement, break cards

Access meaningful choices.

Choice of activity, materials, pacing, partners, location, order of tasks

Request support.

Help cards, visual supports, communication scripts, accessible AAC

Influence participation.

Opportunities to pause, modify, negotiate, or revisit activities

Understand expectations.

Visual schedules, predictable routines, clear transitions

Engage with reduced barriers.

Sensory supports, flexible seating, adapted materials, environmental modifications

What this might look like...

Traditional Approach	Assent-Supportive Modification	Example
Break after worksheet	Break available when requested	Learner uses break card after 5 minutes rather than waiting until worksheet is finished
Verbal directions only	Multiple communication supports	Visual schedule, demonstration, and AAC available
Teacher chooses all materials	Shared decision-making	"Would you like markers or colored pencils?"
Immediate prompting after hesitation	Pause, observe, and offer support	Wait 5–10 seconds, then ask, "Would you like help or more time?"
Same expectations every day	Adjust for context	Shorten activity after poor sleep or sensory overload while maintaining learning goals

Key message:

Assent-supportive environments do not eliminate expectations—they reduce unnecessary barriers while expanding opportunities for communication, choice, and meaningful participation.



TEACHING OTHERS: From Strategic Questioning to Assent-Based Decision Making



Strategic Questions Help Us To....

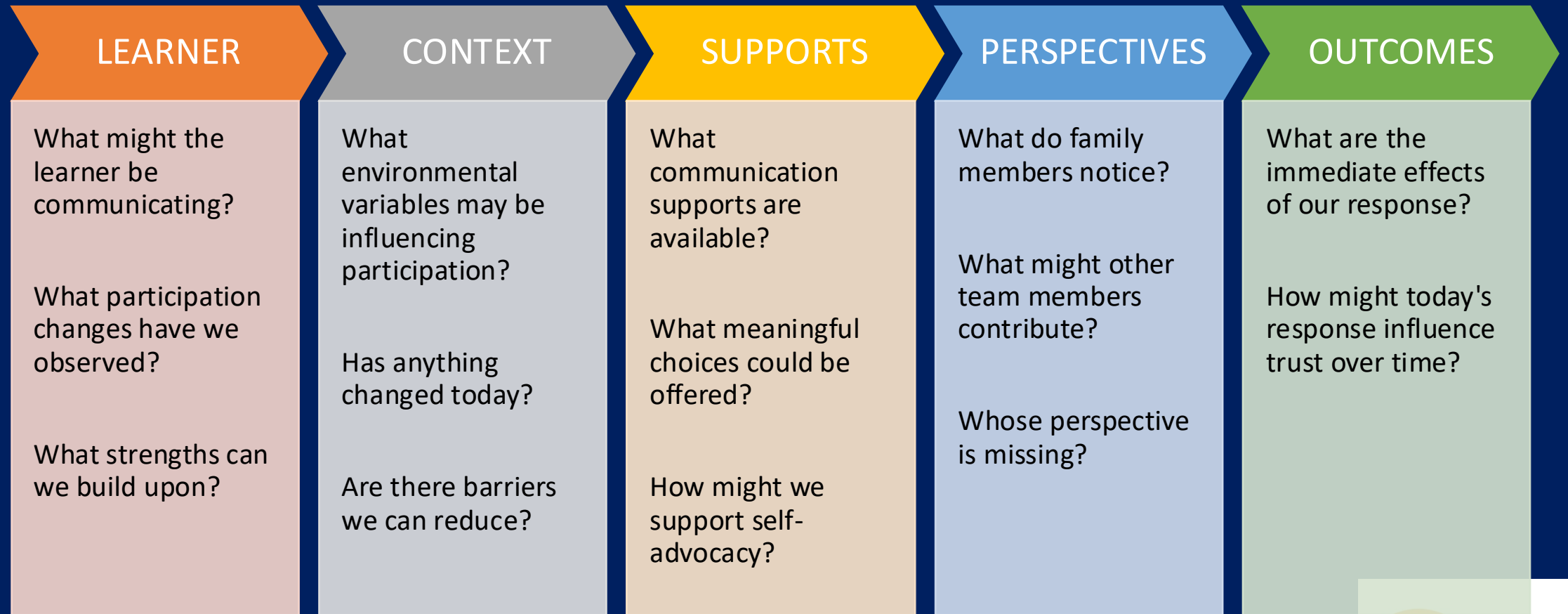
- Slow down interpretation before responding
- Make assumptions visible
- Recognize communication beyond spoken language
- Consider context before drawing conclusions
- Support autonomy and meaningful participation
- Promote interdisciplinary collaboration
- Build individualized understanding over time
- ...and, *make this process automatic*

Key Message:

We can't always know exactly what a learner is communicating—but we can ask better questions before making decisions.



Interdisciplinary Strategic Questions for Assent-Supportive Practice



Let's revisit Amina 

What We Observe	Context to Consider	Strategic Questions	Possible Team Response
Turns away from materials	Poor sleep, sensory overload, unfamiliar environment	What might Amina be communicating? What supports might be needed?	Pause, reduce demands, offer a break or meaningful choice, observe for additional communication
Reduced vocalization	AAC unavailable, fatigue, illness	Has communication become less accessible? How can we increase communication opportunities?	Restore AAC access, offer alternative communication methods, allow additional processing time
Moves away from activity	Extended work period, changing motivation, environmental barriers	Is a break, modification, or different approach needed?	Offer a break, modify the activity, provide choices, revisit later if appropriate
Repeated disengagement during the same activity	Pattern occurring across days or settings	Could this represent assent withdrawal? What additional information do we need?	Gather interdisciplinary perspectives, review patterns over time, revise the individualized assent protocol

Strategic questioning is not the endpoint—it is how we develop individualized supports and protocols.

ONE Possible Individualized Assent Protocol for Amina.

Assent Indicators	Assent Withdrawal Indicators	Individualized Team Response
Approaches materials	Turns body away	Pause and observe before increasing prompts
Selects "more" on AAC	Places materials down	Assess context and communication access
Re-engages after breaks	Moves away from activity	Offer meaningful choices or modifications
Smiles and reaches	Reduced vocalization	Consider sensory, physiological, and environmental factors before responding

Assess Outcomes

Were learner communication and preferences recognized?

- Did the learner have meaningful opportunities to communicate preferences and needs?
- Were multiple forms of communication acknowledged?
- Did the environment support meaningful participation?

Were barriers to participation reduced?

- Were communication, choice, and self-advocacy supported?
- Did the learner have meaningful ways to influence what happened next?

Did decisions reflect context?

- Were contextual variables (e.g., communication access, sensory needs, health, fatigue, relationships) considered before responding?
- Were strategic questions used rather than assumptions?

Did we promote autonomy while achieving meaningful outcomes?

- Were socially significant goals addressed?
- Were teaching strategies individualized and responsive?
- Was participation increasingly self-directed over time?

Did we strengthen trust and relationships?

- Did interactions support rapport, dignity, and psychological safety?
- Was the learner more willing to engage over time?
- How did caregivers and other team members perceive the process?

Syed + friends, in progress!

There may not be a perfect/“exactly right” solution.

What might the learner be experiencing?

- If we are unsure, consider – what would your experience have been?
- What may the experience of someone you love have been?

What is the best decision we can make when considering...

- Supporting autonomy
- Knowing the learner
- Understanding the environment
- Affirming practices

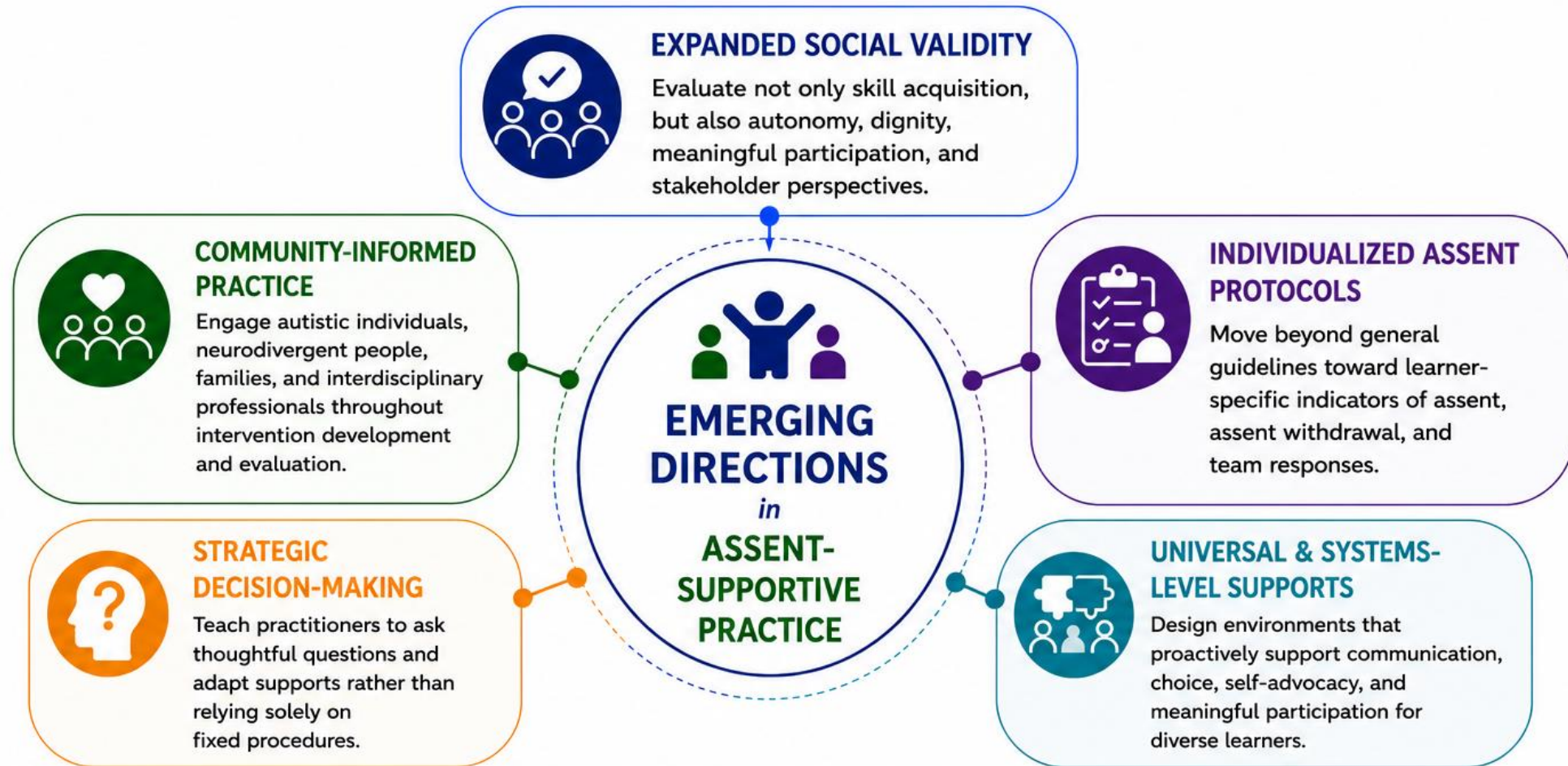
IMPORTANT: Following up on decisions

- How does it effect the learner in the moment?
- What is the longer-term impact?

“Old” Instinct	Assent-Based Shift
Learner is required to participate	Understand participation
Increase our prompting	Investigate communication
Learner must complete the task	Preserve autonomy and trust
Asking: “How do I gain compliance?”	Asking: "What is the learner communicating?"
Focusing on immediate outcomes: “What do I think needs to happen right now?”	Focusing on long-term self-advocacy: “What decision might I make that can best support self-determination and dignity for this learner?”

Emerging Directions in Assent-Supportive Practice

We are moving beyond *whether* assent matters to *how* we embed assent-supportive practices across systems.



Assent-supportive practice is not a checklist.

It is an ongoing commitment to listening, learning, collaborating, and continually refining how we support autonomy and meaningful participation.



One example

Our team is currently engaging in focus groups with autistic adults, neurodivergent adults, helping professionals, and caregivers to help inform the development of an assent-based ABA approach. This information will guide a study assessing the impact of individualized assent-based protocols.

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Key Takeaways

- ✓ Assent is individualized and ongoing.
- ✓ Participation does not necessarily indicate willingness.
- ✓ Context shapes interpretation.
- ✓ Build environments that support communication, choice, and self-advocacy.
- ✓ Teach strategic thinking—not just procedures.



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SMALL CHANGES MATTER.

- What's one small thing you could do this week towards assent-supportive practices?
 - *Observing at least one time every session before responding.*
 - *Add two meaningful opportunities for choice.*
 - *Ask three strategic questions.*
 - *Recognize four new communication signals.*
 - *Share one idea with a colleague.*

Assent-supportive practices and meaningful participation are built through thoughtful observations, strategic questioning, and individualized supports.

Small, intentional shifts create more autonomy-supportive and affirming environments.

Reflections & Discussion



THANK YOU for today!!

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