Skill Building Opportunities: The Key to Unlocking Supported Decision Making Access

NRC-SDM SYMPOSIUM

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The SC Supported Decision Making Project

- A collaborative between P&A, our state's PTI – Family Connection of SC, Arc of SC, and Able SC.
- Funded by the SC DD Council
- Three year grant ends June 30, 2019
- Driven by Able South Carolina, a Center for Independent Living
- Important for this effort to be disability rights driven, IL philosophy centered

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BY THE END OF THIS TALK, EVERYONE WILL…

- Discuss the role of the IEP process in SDM
- State the purpose and describe the function of the “Stop, Look, and Listen” SDM tool
- Complete their own “Stop, Look, and Listen” tool
- Receive access to paper and electronic copies of the tool for their own use

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What Are We Building Capacity Towards?

Use of SDM and decreased reliance on unnecessary guardianship

Culture and Systems Change

- Challenging expectations about capacity by assuming capacity
- Defying deficits-driven conversations about disability
- Normalizing the need for supports and (lowercase) supported decision-making
- Addressing perceived deficits with supports AND robust skill building opportunities

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Barriers Along the Way

- One-sided/lacking conversations about age of majority in the IEP process
- Known deficits remaining unaddressed or without consideration of implications for adulthood
- Assumptions of dependence

Two Common Scenarios Approaching Age of Majority

Scenario 1: Families have assumed or been told that adult guardianship is a must. We not only presume incompetence, we presume lifelong incompetence resulting from a disability

- Attorney in AZ's website: https://susansandys.com/adult-guardianship/
- Especially tricky in that a move towards guardianship may be catalyzed by a parent's love and care for a son or daughter

Two Common Scenarios Approaching Age of Majority (Cont'd)

Scenario 2: Something triggers an overwhelming fear of an unacceptable risk

- Doctor's, service providers, attorneys, and educators pass along the message that parents will be in some way edged out of the process, recommending guardianship (Jameson et al., 2015)
- Failure to obtain guardianship is akin to parental negligence
- A connotation of independence as "all or nothing"

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Two Common Scenarios Approaching Age of Majority (Cont'd)

Three things are not typically understood by parents in either scenario:

- Less restrictive alternatives to guardianship
- Full breadth of guardianship
- How to channel concern into proactive skill building for independence

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To Date…

Much of our work around the country has centered on capacity building around knowledge of less restrictive alternatives to guardianship

- Lots of great tools to assess and plan for support in areas of deficit in critical adult decision making areas
- With support from the NRC-SDM, we set out to address building capacity for proactive movement from IEP teams and families around areas of support need

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NRC-SDM State Project

"Stop, Look, and Listen: Planning for Independence and Adult Decision Making Support"

- Funded by the National Resource Center for Supported Decision-Making
- Draft assessment piloted with families of youth with IEPs by two SC school districts
- Tool finalized in May 2019 and released for the first time in this session!

Purpose of Tool

Proactive, constructive age of majority conversations in annual review IEP meetings

- Taking a hard look at opportunities to learn and practice critical skills
- If we know there are gaps in the acquisition of critical decision making skills, the role of the IEP team is to…

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Where Does SDM Fit in the IEP Process?

According to IDEA (Sec. 300.347(b)(2):

"Beginning at age 16 (or younger, if determined appropriate by the IEP team), a statement of needed transition services for the child, including, if appropriate, a statement of the interagency responsibilities or any needed linkages."

Transition Services (Sec. 300.29) are:

"…a coordinated set of activities for a student with a disability that--(1) Is designed within an outcome-oriented process, that promotes movement from school to post-school activities, including postsecondary education, vocational training, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation; (2) Is based on the individual student's needs, taking into account the student's preferences and interests; and (3) Includes--(i) Instruction; (ii) Related services; (iii) Community experiences; (iv) The development of employment and other post- school adult living objectives; and (v) If appropriate, acquisition of daily living skills and functional vocational evaluation."

Transition Services and "Stop, Look, and Listen"

- Transition Services, as spelled out in the IEP, can and should address skill deficit related to adult decision making

- As J. Martinis points out, failing to do so is malpractice on the part of educators

- Pointing out professional malpractice doesn't always result in friendly conversation…

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The Goal of the Tool

- The “Stop, Look, and Listen” tool seeks to help families and professionals to understand the role of the environment in contributing to skill deficits
  - Just highlighting deficits plays into a cultural normative tendency to attribute deficits to disability
  - SDM is inherently driven by the Social Model of disability – understanding how the environment shapes or fails to shape independence in adult decision making is critical
  - Most logical people would follow that if one has had minimal opportunities to learn or practice a skill, there is little reason to fault an individual for not possessing that skill

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The Tool: An Overview

Stop, Look, and Listen
Part 1: Assessing Opportunities to Learn and Practice in Areas of Adult Decision Making

Who is Completing This Assessment? ☒ Decision Maker ○ Parent ○ Teacher ○ Other: _____

Step 1: For each skill in Part 1, decide how often you have had the opportunity to practice or learn this skill (not at all, some, a lot) and **check the *one* box that fits best**. **Step 2:** Compare the results of the decision maker with the results of a supporting adult, highlighting the areas of agreement where there is little or no opportunity to learn or practice an important, adult skill. **Step 3:** Go on to Part 2 and begin the discussion as a family or as an IEP team on increasing opportunity for skill-building in the areas most important to the independence of that person.	**I have had the opportunity to learn and practice this skill a lot.**	**I have had some opportunities to learn and practice this skill.**	**I have not had opportunities to learn and practice this skill.**
Finances			
Making small purchases (e.g. lunch, snacks, clothing, etc.)	○	○	○
Keeping track of purchases and bills (i.e. budgeting)	○	○	○
Managing a bank account (e.g. online banking)	○	○	○
Understanding when someone is trying to take advantage of me financially	○	○	○
Making big decisions about money (e.g. opening an account, signing a lease, or obtaining a credit card)	○	○	○
Paying bills	○	○	○
Relationships			
Understanding personal boundaries	○	○	○
Speaking up if something doesn't feel right	○	○	○
Recognizing abuse or exploitation	○	○	○
Making choices about romantic relationships	○	○	○
Making choices about sex	○	○	○

“Stop, Look, and Listen” Part II

- Part II of the tool seeks to move from findings about opportunities to a discussion of increasing opportunities
  - The ideal output is annual IEP goals in areas currently lacking opportunity
  - Feedback from teachers piloting the tool indicates that examples of goals would have been helpful to include, but doing so is somewhat problematic for many reasons

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Scoring

- No prescriptive method of scoring is offered, but the utility of this instrument as a transition assessment is clear
  - “Appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills” [§300.320 (b) (1)]

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“Stop, Look, and Listen” Guidelines for Promoting Independence

- The tool ends with some of the most important concepts we hoped for IEP teams to take away

- This is the messaging we hope to continue carrying into everything we do with SDM in SC:

+ Independence is rarely “all or nothing.” We increase our independence with a skill as we are exposed to it and the natural consequences for doing it or not doing it. If an individual is not currently performing a skill, it does not mean they cannot grow in that area. Needing support in areas is a natural part of growing up for all people.

+ Connect with sources of support. Youth with disabilities may be used to others providing support in their daily lives without them asking for it. For this reason, youth may need help in defining the possible roles of adult supporters, problem solving, and requesting that support.

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“Stop, Look, and Listen” Guidelines for Promoting Independence (cont’d)

+ Avoid assumptions about capacity to understand or grow in an area. Try not to avoid learning opportunities because of failures in other areas or the difficulty of a task. Independence from increased responsibility can be a great incentive for learning new skills.

+ Nationally, the Individuals with Disabilities in Education Act (IDEA) mandates that transition planning begin in the IEP no later than age 16. In South Carolina, transition planning must begin by age 13. The purpose of this window of time is to purposefully plan for the transition to adult life, and the IEP can and should set a path forward for learning critical skills. With a strong IEP and a home life that supports independence, incredible things are possible.

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“Stop, Look, and Listen”: Deeper Dive

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“Stop, Look, and Listen”
Pilot Teacher Feedback: What Went Well?

“It ask realistic questions and is super helpful to students, parents and myself”

“Absolutely, everything. It's quite comprehensive, teacher/user-friendly, but allows you to gain much-needed data that supports the development of an effective PLAAFP”

“I thought that allowing the students to respond to the tool themselves was very beneficial. It allowed me to see what they thought about each area and compare it to their actual skills or knowledge”

“Helped to address specific weaknesses”

“Fairly easy to assess”

“It allowed me to hit on specific life skills when writing IEP goals”

“Having the students score themselves”

“Comparing family response to my own”

“The ease of use”

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“Stop, Look, and Listen”
Pilot Teacher Feedback: What Could Have Been Better?

“Just need more practice getting parents to complete”

“There were many statement marked no opportunity for the freshmen”

“While parent completion was not necessary, it would have been beneficial to get more feedback from them. Most of the parents failed to return the tool even after reminders were given”

“Parental input on a couple was drastically different from teacher input”

“Didn't feel as it was so applicable to my self contained students with limited abilities”

“I need examples of how to write a proper IEP goal using this tool”

“Difficult to get parents to complete it when they do not attend meetings”

“One parent answered the highest in all categories”

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Discussion: Implications for Future Use

- Expectations of students with high intensity support needs may keep this tool from being used

- Difficulties with family involvement will naturally extend to this tool being used to its fullest potential

- Dealing with discrepancies in ratings will vary –insight from those differences is incredibly instructive by itself but was too much of a “rabbit hole” for narrative sections

- Perceptions of transition services and their connection to postsecondary goals will affect how and IEP team conceptualizes this tool’s use

- “Stop, Look, and Listen” confronts cultural norms through a new lens
  - It is just a start

Where We've Been and Where We Hope to Go in SC

- More capacity building – website, tons of family counseling and trainings for case managers, educators, and attorneys; manuals for families and professionals
  - Follow this link to explore!: www.scsupporteddecisionmaking.org
  - Lots and lots of folks are still being given legal advice in IEP meetings
  - Medical providers are often behind recommendations for guardianship

- State legislation recognizing SDM

- Trainings and resources for medical providers

- Data! More transparency on guardianship proceedings

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Questions?

Email me anytime!

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