

THE UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

Evidence-based Practices: What Works and Where Do We Go From Here

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Presentation Overview

- Discuss what we know about evidence-based practices in autism
- Discuss what we don't know and who has been left out of that research
- Discuss some ways for moving this work forward
 - With a focus on community engaged research and implementation science and practice

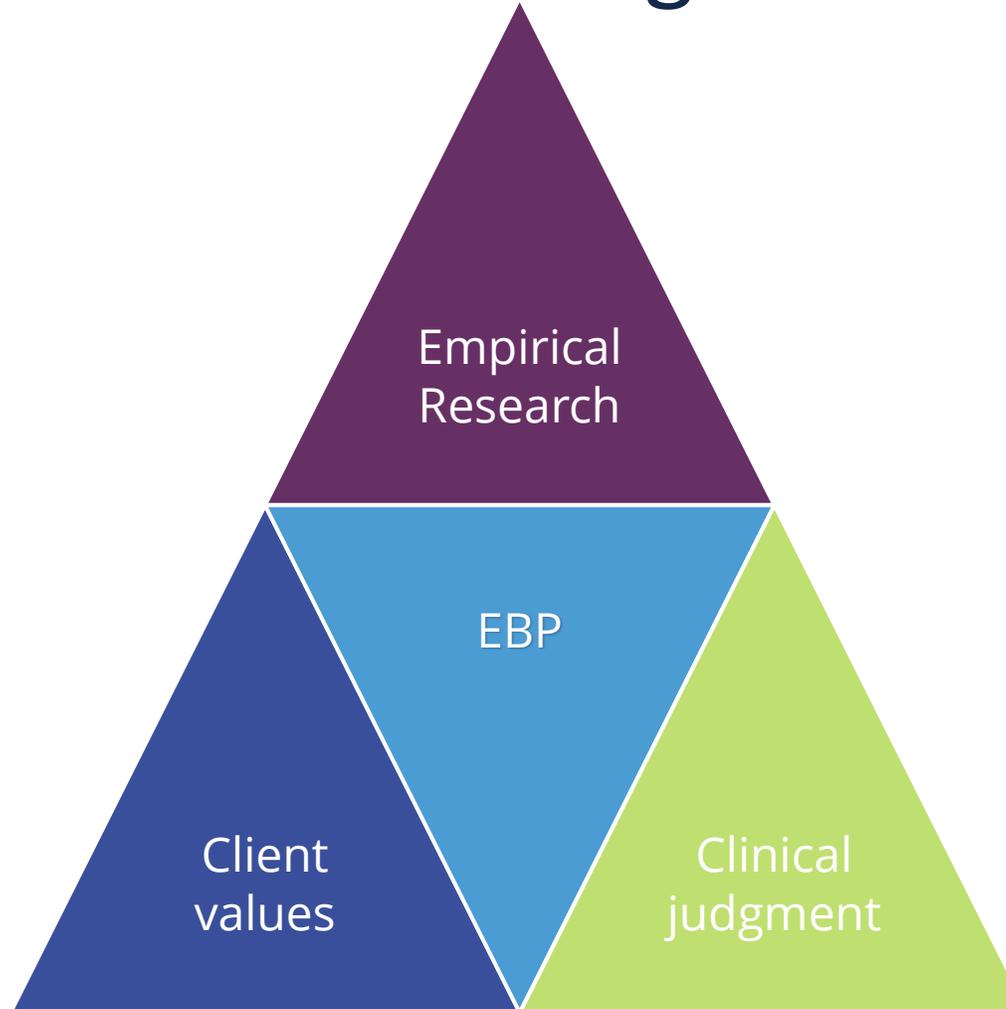


Evidence-based Practice

Evidence-based medicine: “The conscientious, explicit, and judicious use of **current best evidence in making decisions** about the care of individual patients. The practice of evidence-based medicine means **integrating** individual **clinical expertise with** the best available external clinical evidence from **systematic research.**”

(Sackett, Rosenburg, Muir Gray, Haynes & Richardson, 1996).

Evidence-based Practice Triangle



Stop & Reflect





Ethical Dilemma of EBP

Has anyone ever experienced a client's or family's preference being in disagreement with the evidence?

National Clearinghouse on Autism Evidence & Practice (NCAEP)



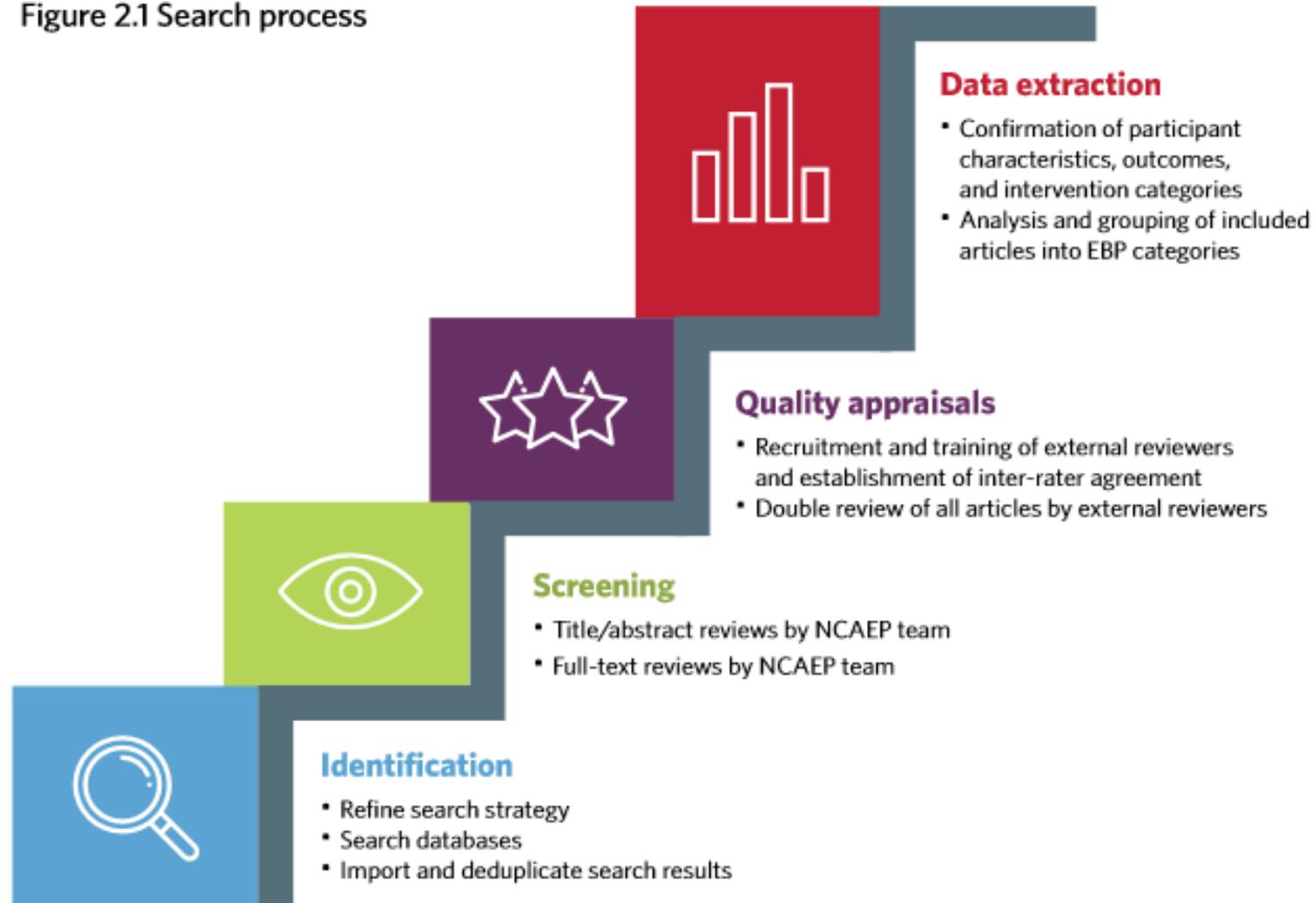
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Current Review of EBPs

The screenshot shows the homepage of the National Clearinghouse on Autism Evidence & Practice (NCAEP). The header features the organization's logo, a 'GIVE NOW' button, social media icons for Facebook and Pinterest, and a search bar. The main navigation includes links for Home, About NCAEP, News & Updates, and Research & Resources. A prominent orange banner announces that the new report on Evidence-Based Practices is complete and ready for viewing. Below this, three main content areas are presented: 'BRIDGING SCIENCE AND PRACTICE' with a 'LEARN MORE' button, the '2020 EVIDENCE-BASED PRACTICES REPORT' with a 'DOWNLOAD HERE' button, and 'AUTISM FOCUSED INTERVENTION RESOURCES AND MODULES' (AFIRM) with a 'LOGIN' button.

Current Review of EBPs

Figure 2.1 Search process



3rd Generation

- Screened more than 31,000+ articles published from 2012-2017
- 634 included for full text review



IDENTIFYING EBPs

How many EBPs?

28

Steinbrenner et al., 2020

<https://ncaep.fpg.unc.edu/research-resources>

Evidence-Based Practices for Children, Youth, and Young Adults with Autism

Jessica R. Steinbrenner, Kara Hume, Samuel L. Odom,
Kristi L. Morin, Sallie W. Nowell, Brianne Tomaszewski,
Susan Szendrey, Nancy S. McIntyre,
Şerife Yücesoy-Özkan, & Melissa N. Savage



National Clearinghouse on Autism Evidence
and Practice Review Team



Evidence-Based Practices

- A set of manualized interventions grouped within established EBP categories now themselves have sufficient evidence to be classified as evidence-based: PECS[®], PRT, JASPER, Milieu Training, Project ImPACT, Stepping Stones/Triple P, Social Stories[™], PEERS[®], Mindreading, and FaceSay[®].

Antecedent-Based Interventions

Augmentative and Alternative Communication

Behavioral Momentum Intervention

Cognitive Behavioral/Instructional Strategies

Differential Reinforcement of Alternative, Incompatible, or Other Behavior

Direct Instruction

Discrete Trial Training

Exercise and Movement

Extinction

Functional Behavioral Assessment

Functional Communication Training

Modeling

Music-Mediated Intervention

Naturalistic Intervention

Parent-Implemented Intervention

Peer-Based Instruction and Intervention

Prompting

Reinforcement

Response Interruption/Redirection

Self-Management

Sensory Integration[®]

Social Narratives

Social Skills Training

Task Analysis

Technology-Aided Instruction and Intervention

Time Delay

Video Modeling

Visual Supports

Steinbrenner et al., 2020

Find the EBP definitions at <http://go.unc.edu/2020EBPs>.

Changes in Practices

New Practices

- **Augmentative & Alternative Communication (AAC)**
- **Behavioral Momentum (BM)**
- **Direct Instruction (DI)**
- **Music-Mediated (MMI)**
- **Sensory Integration (SI)**

Merged Practices

- **PECS → AAC**
- **PRT → Naturalistic**
- **Scripting → Visual Supports**
- **Structured Play Groups → PBII**

AFIRM

E-learning modules for 28 EBPs:
<http://afirm.fpg.unc.edu/>

Target audience:

- Special educators
- General education teachers
- Paraeducators
- Related service personnel
- Early interventionists

Planning, Selecting, and Monitoring EBPs

The screenshot shows the AFIRM website homepage. At the top left is the AFIRM logo, a circle divided into three overlapping colored segments (purple, yellow, blue). To its right is the text "Autism Focused Intervention Resources & Modules". In the top right corner, there are "Login" and "Sign Up" buttons. Below the header is a navigation menu with "AFIRM Modules", "Timely Toolkits", "Earn CE Credits", and "Selecting EBPs". The main content area is split into two columns. The left column is a green login form with fields for "Username or e-mail" and "Password", a "Log in" button, and links for "Create new account" and "Request new password". The right column is a light green box with text: "Access free AFIRM online modules and resources for evidence-based practices identified by the National Clearinghouse on Autism Evidence & Practice on Autism Spectrum Disorder (ASD). Sign up now." and "Free Timely Toolkits: The resources included in our Timely Toolkits are designed to support autistic individuals, their caregivers, and related professionals as they navigate through specific global and/or local events." Below this is a blue banner with three sections: "Earn a free professional development certificate for completing each EBP module" with a "View modules" button; "Learn with AFIRM through engaging case examples, videos, and interactive assessments" with a "Find out more" button; and "Download resources and materials that support your use of EBPs with children and youth with ASD" with a "View Resources" button.

EBP Database

The EBP database is designed to help you in the EBP selection process. First, select the relevant age range and choose the domain you are targeting. Next, click “Apply”. The information will be presented in two ways.

On the right side of the screen you will see all of the included articles that target your selected age range and domain, along with the associated EBPs.

On the left side of the screen you will see the menu of EBPs that have proven effective in addressing the selected outcome for the targeted age range. You will also see the number of articles associated with each EBP in parentheses after the EBP. You can click the EBP to see the articles that contribute to the evidence base for each practice.

Age

6-11.9 years

Domains

Play

APPLY

CLEAR

EBP

Antecedent-based interventions (1)

Augmentative and alternative communication (2)

Displaying 1 - 40 of 65

[A comparison of video modeling with in vivo modeling for teaching children with autism](#)

Age(s): 6-11.9 years

Domain(s): Communication, Play, Social

EBP(s): Video modeling

Name of EBP	Augmentative and Alternative Communication (AAC)
Definition of EBP	<p>Augmentative and Alternative Communication (AAC) interventions use and/or teach the use of a system of communication that is not verbal/vocal including aided and unaided communication systems. Unaided communication systems do not use any materials or technology (e.g., sign language and gestures). Aided communication systems include low tech systems (e.g., exchanging objects/ pictures or pointing to letters) and extend to high tech speech generating devices (SGDs) and applications that allow other devices (i.e., phones, tablets) to serve as SGDs. Methods of teaching AAC use are also included in this category (e.g., Aided Language Modeling) which may include other EBPs such as prompting, reinforcement, visual supports, and peer-mediated interventions.</p> <ul style="list-style-type: none"> Manualized Interventions Meeting Criteria: Picture Exchange Communication System® (PECS®; Bondy and Frost, 1985).

Outcome Areas		Age Ranges					
		0-2 Toddlers	3-5 Preschoolers	6-11 Elementary School	12-14 Middle School	15-18 High School	19-22 Young Adults
	Communication	✓	✓	✓	✓	✓	
	Social	✓	✓	✓		✓	
	Joint attention	✓	✓	✓			
	Play	✓	✓	✓			
	Cognitive						
	School readiness						
	Academic/ Pre-academic		✓	✓			
	Adaptive/ self-help						
	Challenging/ Interfering behavior		✓	✓			
	Vocational						
	Motor					✓	
	Mental health						
	Self-determination						

References

1. Agius, M. M., & Vance, M. (2016). A comparison of PECS and iPad to teach requesting to pre-schoolers with autistic spectrum disorders. *Augmentative and Alternative Communication*, 32(1), 58-68. <https://doi.org/10.3109/07434618.2015.1108363>
2. Ali, E., MacFarland, S. Z., & Umbreit, J. (2011). Effectiveness of combining tangible symbols with the Picture Exchange Communication System to teach requesting skills to children with multiple disabilities including visual impairment. *Education and Training in Autism and Developmental Disabilities*, 46(3), 425-435.
3. Almirall, D., DiStefano, C., Chang, Y.-C., Shire, S., Kaiser, A., Lu, X., Nahum-Shani, I., Landa, R., Mathy, P., & Kasari, C. (2016). Longitudinal effects of adaptive interventions with a speech-generating device in minimally verbal children with ASD. *Journal of Clinical Child & Adolescent Psychology*, 45(4), 442-456. <https://doi.org/10.1080/15374416.2016.1138407>
4. Alzayer, N. M., Banda, D. R., & Koul, R. (2017). Teaching children with autism spectrum disorder and other developmental disabilities to perform multistep requesting using an iPad. *Augmentative and Alternative Communication*, 33(2), 65-76. <https://doi.org/10.1080/07434618.2017.1306881>

Steinbrenner et al., 2020

Outcomes

Selecting EBPs

Steinbrenner et al., 2020

Table 3.5 Outcomes identified across review periods

Domain/Instructional Outcome	Definitions	1990-2011 (n)	2012-2017 (n)	1990-2017 (n)
Academic/Pre-academic	Outcomes broadly related to performance on tasks typically taught and used in school settings	55	96	151
Adaptive/Self-help	Outcomes related to independent living skills and personal care skills	52	53	105
Challenging/Interfering behavior	Outcomes related to decreasing or eliminating behaviors that interfere with the individual's ability to learn	147	121	268
Cognitive	Outcomes related to performance on measures of intelligence, executive function, problem solving, information processing, reasoning, theory of mind, memory, creativity, or attention	15	22	37
Communication	Outcomes related to ability to express wants, needs, choices, feelings, or ideas	173	159	332
Joint attention	Outcomes related to behaviors needed for sharing interests and/or experiences	36	27	63
Mental health	Outcomes related to emotional well-being	1	16	17
Motor	Outcomes related to movement or motion, including both fine and gross motor skills, or related to sensory system/sensory functioning	17	16	33
Play	Outcomes related to the use of toys or leisure materials	73	50	123
Self-determination	Outcomes related to self-directed actions in setting and achieving goals or making decisions and problem-solving	0	2	2
School readiness	Outcomes related to task performance versus task content or curriculum area (e.g., on task behavior, engagement)	63	46	109
Social	Outcomes related to skills needed to interact with others	152	150	302
Vocational	Outcomes related to employment or employment preparation or relate to technical skills required for a specific job	11	20	31

Steinbrenner et al., 2020

IMPLEMENTING EBPs

AFIRM Supplemental Materials

Implementation checklist

Step-by-step practice guide

Parent's guide

Tip sheet for professionals

Data sheets

Evidence-base

The image displays two documents from the AFIRM (Autism Focused Intervention Resources & Modules) suite. The top document is the 'Implementation Checklist' for Antecedent-Based Interventions (ABI). It includes a header with the AFIRM logo and contact information, followed by a table for recording observations and dates. The checklist is organized into three main steps: 'STEP 1: PLANNING', 'STEP 2: USING', and 'STEP 3: MONITORING'. Each step contains several sub-tasks with checkboxes for completion. A note states: 'If the answer to any of the above questions is "No," review the process of how to select an EBP.' The bottom document is the 'Prompting (PP) Implementation Checklist', which follows a similar structure with three steps: 'Step 1: Planning', 'Step 2: Using', and 'Step 3: Monitoring'. It includes a 'Before you start' section with questions and a 'Have you...' section with checkboxes. Both documents are published by the National Professional Development Center on ASD in 2015.

Step-by-Step Guide

AFIRM Autism Focused Intervention Resources & Modules

Visual Support Step-by-Step

BEFORE YOU START

Each of the following points is to address so that you can be likely to address the learner student.

Have you found out more?

- Established a goal or when the behavior skill is, and how skill is mastered
- Identifying evidence

If the answer to a process of how to

This practice guide outlines how to plan for, use, and monitor the visual supports practice.

Keep in mind that the three categories of visual supports are:

- Visual boundaries
- Visual cues
- Visual schedules

While each category is slightly different, the practice guide is applicable to all. When unique features are tied to a specific category, we will identify them through examples or cautions.

AFIRM Autism Focused Intervention Resources & Modules

Visual Supports

National Professional Development Center

AFIRM Autism Focused Intervention Resources & Modules

Step-by-Step Guide

Antecedent-Based Interventions

For more information, please visit: <https://afirm.fpg.unc.edu/>

ABI

This step-by-step practice guide outlines how to plan for, use, and monitor antecedent-based interventions.

BEFORE YOU BEGIN...

Each of the following points is important to address so that you can be sure antecedent-based interventions is likely to address the target goal/behavior/skill of your learner with autism.

HAVE YOU FOUND OUT MORE INFORMATION ABOUT...?

- Identifying the target goal/behavior/skill...?
- Collecting baseline data through direct observation...?
- Establishing a target goal or outcome that clearly states when the behavior will occur, what the target goal or outcome is, and how team members and/or observers will know when the skill is mastered...?

If the answer to any of the above questions is 'No,' review the process of how to select an appropriate EBP (<https://afirm.fpg.unc.edu/selecting-EBP>).

For more information about antecedent-based interventions, please visit <https://afirm.fpg.unc.edu/>.

Keep in mind that antecedent-based interventions can be used to decrease interfering behaviors and increase engagement.

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The National Professional Development Center on Autism Spectrum Disorder

ABE

Sara et al. Updated 2022

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AFIRM Autism Focused Intervention Resources & Modules

Antecedent-Based Interventions

For more information, please visit: <https://afirm.fpg.unc.edu/>

STEP 1: PLANNING FOR ABI

The planning step details the initial steps and considerations involved to prepare for using antecedent-based interventions with a learner with autism. Be sure to use a functional behavior assessment (FBA) to identify and define the interfering behavior.

1.1 Identify and define the interfering behavior through an FBA

To assist in identifying a behavior that interferes with learning and/or development, team members should complete a functional behavior assessment (FBA). For more information, visit the Functional Behavior Assessment module.

1.2 Collect data using direct observation methods

To collect data on the interfering behavior, team members should use A-B-C data charts. A-B-C data charts help team members identify what happens directly before the behavior (antecedent), describe the behavior, and determine what happens directly after the behavior (consequence).

- This ABC Data Chart can be used to record observations of the learner's behavior.

1.3 Review data collected from direct observations

Data tables (commonly referred to as scatterplots in the FBA literature) can be used to help teams determine possible functions of the behavior, when the behavior is occurring, and times of the day when an intervention might be implemented to reduce the interfering behavior.

- This Scatterplot can be used to identify patterns in the learner's behavior.

1.4 Develop a hypothesis statement and overall goal

Based upon the information gathered, the team develops a hypothesis statement that includes the following:

- The setting events, immediate antecedents, and immediate consequences that surround the interfering behavior.
- A restatement and refinement of the description of the interfering behavior that is occurring.
- The function the behavior serves (i.e., get/obtain, escape/avoid).
- This Planning Worksheet can be used to develop a hypothesis and goal for the learner's behavior.

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ABE

Sara et al. Updated 2022

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Tips for Professionals


Autism Focused Intervention Resources & Modules

Visual Supports (VS) ---Tip Sheet for Professionals---

Visuals Supports are...

- an evidence-based practice for children and youth with autism spectrum disorder (ASD) from 3 to 22 years old that is implemented in a variety of ways across multiple settings;
- a group of specific interventions that minimize adult support while increasing the independence of learners with ASD. This practice includes visual boundaries, visual cues (graphic organizers, choice boards, and visual instructions) and visual schedules.

Why Use?

- Learners with ASD struggle with verbal instructions of what to do or what will happen next.
- Visual supports present information in a way that helps learners with ASD focus on key elements.
- Visual supports can increase on-task behavior and foster the independence of learners with ASD.

Outcomes

- The evidence-base for VS supports the use of this practice to address the outcomes below:

Early Intervention (0-2)	Preschool (3-5)	Elementary (6-11)	Middle (12-14)	High (15-22)
No studies	Social	Social	Social	Social
	Communication	Communication	Communication	
	Behavior	Behavior	Behavior	
	School Readiness	School Readiness	School Readiness	
	Play	Play	Play	
	Cognitive			
		Motor		
		Adaptive	Adaptive	
		Academic	Academic	

Visual Supports National Professional Development Center


Autism Focused Intervention Resources & Modules

Tip Sheet for Professionals

Antecedent-Based Interventions
For more information, please visit: <https://afirm.fpg.unc.edu/>

ABI

ANTECEDENT-BASED INTERVENTIONS IS...

- An evidence-based practice for children and youth with autism spectrum disorder (ASD) from 0-22 years old that can be implemented in multiple settings.
- Focus on identifying the events that take place immediately before and after an identified interfering behavior in order to modify the environment to change the conditions in the setting that prompt a learner to engage in the behavior.



TIPS:

- Complete an FBA to identify a behavior that interferes with learning and what function that behavior is serving
- Select an ABI strategy that addresses the functioning of the interfering behavior
- Ignore interfering behavior and provide reinforcement to the learner for not engaging in the interfering behavior and for completing a task or activity.

WHY USE WITH LEARNERS WITH AUTISM?

- ABI are designed to prevent the identified interfering behavior from occurring.
- Team members can use ABI to increase engagement and on-task behaviors.
- ABI are easy to implement and require little additional effort by team members

INSTRUCTIONAL OUTCOMES:

- The evidence-base for antecedent-based interventions supports its use to address the following outcomes, according to age range, in the table below:

EVIDENCE-BASE:	Academic	Adaptive	Challenging/Interfering	Communication	Motiv/Health	Play	School readiness	Social
0-2		Yes						
3-5	Yes	Yes	Yes	Yes		Yes		
6-11	Yes	Yes	Yes	Yes		Yes		
12-14	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
15-18	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
19-22		Yes	Yes	Yes	Yes		Yes	Yes

Visual Supports National Professional Development Center


Autism Focused Intervention Resources & Modules

Visual Supports (VS) ---Tip Sheet for Professionals---

Visual Supports VS

This tip sheet was designed as a supplemental resource to help provide basic information about the practice.

For more information visit:
www.afirm.fpg.unc.edu



Antecedent-Based Interventions ABI

This sheet was designed as a supplemental resource to provide basic information about this evidence-based practice for professionals working with learners with autism.

For more information about this selected evidence-based practice, please visit <https://afirm.fpg.unc.edu/>.

Antecedent-Based Interventions
For more information, please visit: <https://afirm.fpg.unc.edu/>

STEPS FOR IMPLEMENTING

- 1. PLAN**
 - Identify vis maintain t
 - Develop/f based on
 - Organize
- 2. USE**
 - Teach
 - Fade crite
 - Use sett
- 3. MONITOR**
 - Collect data
 - Analyze data
 - Determine next steps based on learner progress

Antecedent-Based Interventions
For more information, please visit: <https://afirm.fpg.unc.edu/>

STEPS FOR IMPLEMENTING:

- 1. PLAN**
 - Identify and define interfering behavior through an FBA
 - Collect data using direct observation methods
 - Review data collected from direct observations
 - Develop a hypothesis statement and an overall goal
- 2. USE**
 - Select an ABI strategy that addresses the function of the interfering behavior. ABI strategies include:
 - Using learner preferences
 - Changing schedules/routines
 - Implementing pre-activity interventions
 - Using choice-making
 - Altering how instruction is delivered
 - Enriching the environment with sensory stimuli
 - Create lesson plan that includes selected ABI strategy.
 - Ignore interfering behavior.
 - Provide learner with reinforcement.
- 3. MONITOR**
 - Collect data and analyze data on interfering behavior
 - Determine next steps based on learner progress

Visual Supports National Professional Development Center

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Fidelity Checklists and Home Companion Guide



MODULE ONE
REINFORCEMENT

COMPANION GUIDE FOR FAMILIES | Use the Companion Guide for Families to assist with using reinforcement in your home.

The AFIRM for Paras modules were developed for paraprofessionals at elementary schools. However, the practices outlined in the modules can be helpful for families to use at home and can be used with a variety of ages. This companion guide is designed to offer a brief description of steps for reinforcement and provides some ideas of how you might use it in your home.

What is Reinforcement?

Reinforcement is used to increase a desired behavior or skill by giving a child a reward after the desired behavior or skill is used.

Positive reinforcement
When rewards are used to increase a desired skill or behavior.

Token economy
A type of positive reinforcement system in which a child receives a token as a reward each time they use the target skill or behavior. After earning a certain number of tokens, the child earns a reward that they really like (e.g. time on iPad, a favorite show, time with Legos). Tokens can be anything – stickers, check marks, cards, blocks.



What are the steps for using reinforcement?

1. Identify the behavior or task
Choose the behavior that you will focus on while using reinforcement with your child. Think about what you want the child to do, how you would like them to demonstrate the behavior, and when this behavior or task would be performed.





MODULE ONE
REINFORCEMENT

REINFORCEMENT CHECKLIST | Use the Reinforcement Steps in this checklist and gather information from the teacher before using the practice.

General Planning	
WHO	
WHEN DATE	/ /
TIME	
WHERE	
WHAT (Target Skill)	
HOW TO USE	
HOW TO MEASURE	

PLAN	
1. Know reinforcers to use with student	✓
2. Know the reinforcement schedule	
3. Know what data to collect	

USE	
1. Have needed materials ready (reinforcers)	✓
2. Give direction to student to use target skill/behavior (if needed)	
3. Help student use target behavior/skill (if needed)	
4. Give student the reinforcer soon after doing the target behavior/skill	
5. Pair reinforcer with a description of the behavior (*may not always be appropriate)	
6. Follow the reinforcement schedule	
7. Vary the reinforcers used with student	
8. Use reinforcers consistently across activities and/or settings	

MONITOR	
1. Take data on target behavior/ skill	✓
2. Check in with teacher about next steps at least weekly	

AFIRM for Paraeducators

Menu Transcript

- Introduction
 - Welcome
 - Introduction
 - Positive Reinforcement
 - Plan, Use, and Monitor Reinforce...
- Jack
 - Plan
 - Use
 - Monitor
- Lucy
 - Plan
 - Use
 - Monitor
- Examples
- Michael
 - Plan
 - Use
 - Monitor
 - Token Economy
 - Troubleshooting Skills

Module 1: Reinforcement Resources



AFIRM
for Paraprofessionals
Autism Focused Intervention
Resources and Modules

▶ ↻

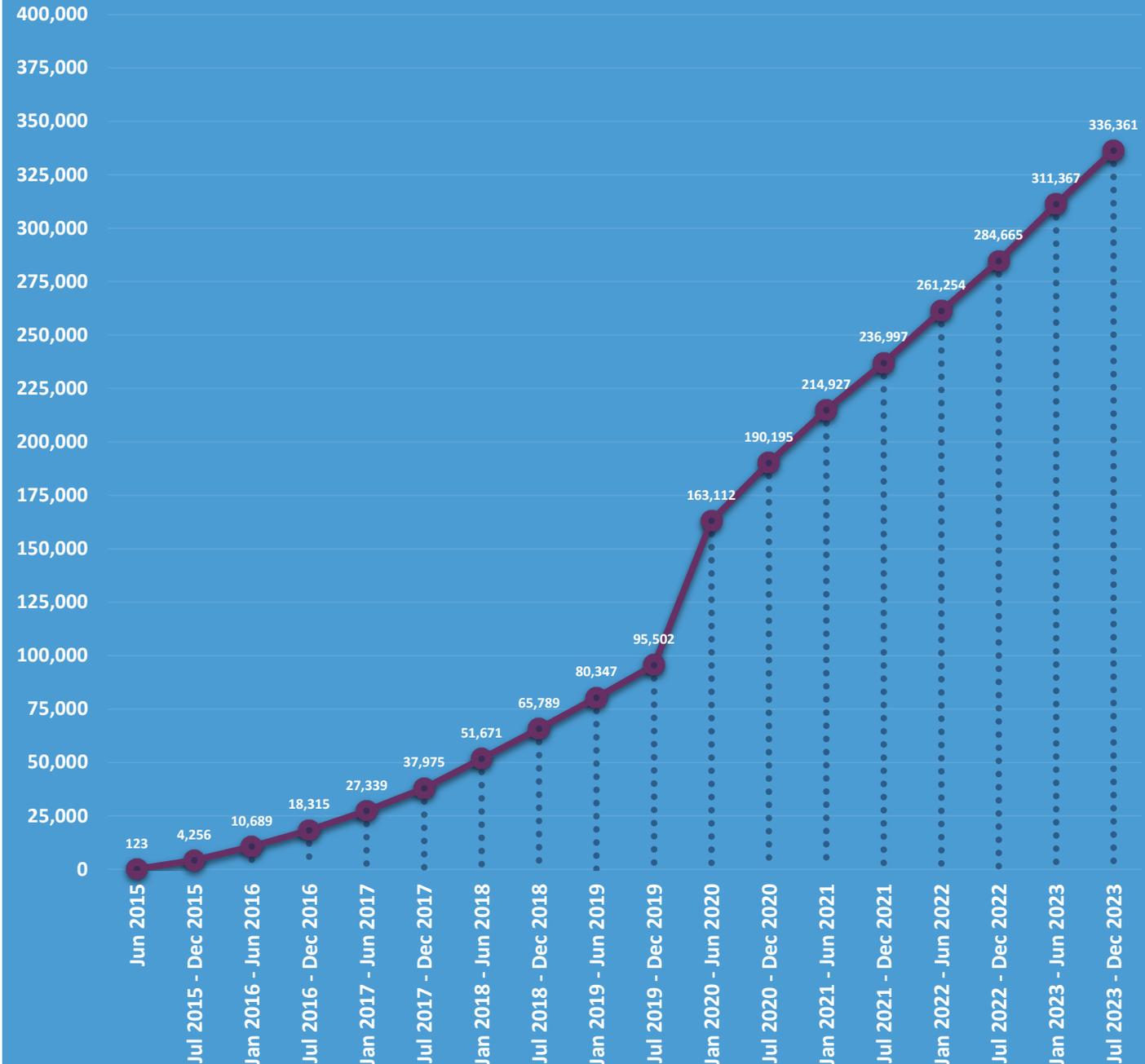
AFIRM METRICS



Autism Focused Intervention
Resources & Modules

- **AFIRM User Growth: 336,361**
 - Averaging 4,140 new users monthly
- **Translations:**
 - Arabic
 - Mandarin
 - Italian

AFIRM User Growth (n=336,361)



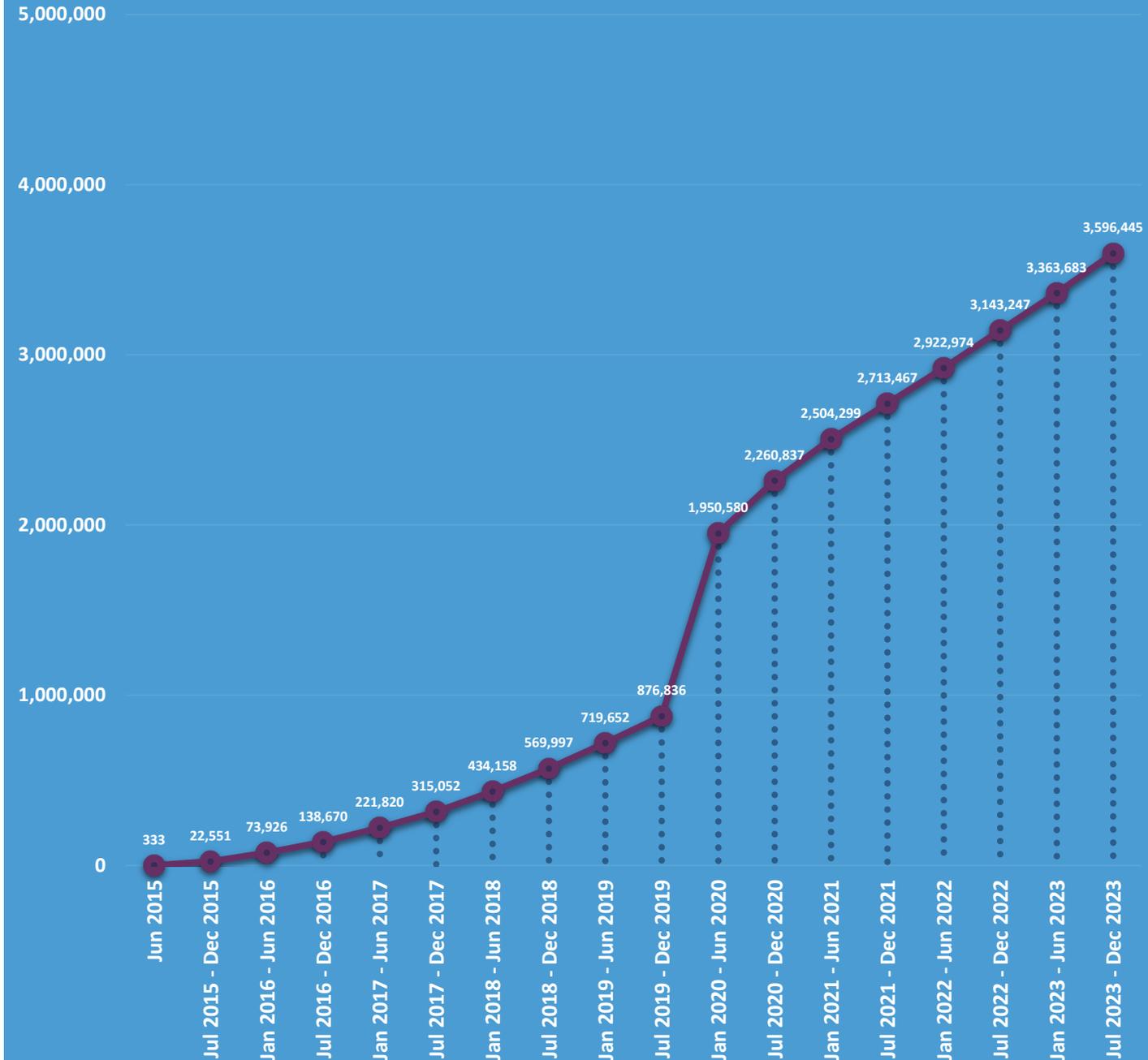
AFIRM METRICS



Autism Focused Intervention Resources & Modules

- **Downloads: 3,596,445**
 - Averaging 36,790 downloads monthly
 - **Top 5 downloaded resources:**
 - 1 – EBP Brief Packet (376,606)
 - 2 – Data Forms (282,896)
 - 3 – Planning Forms (277,170)
 - 4 – Evidence-base (156,449)
 - 5 – Step-by-Step Guide (140,505)

AFIRM User Downloads (n= 3,596,445)



Read the Full Report

- Summary
- Research Article
- Null Findings
- Sensory Integration Companion Guides



<https://ncaep.fpg.unc.edu/research-resources>

The Lancet Commission on the Future of Care and Clinical Research in Autism





Future of care and clinical research in autism

An international perspective on the future of care and clinical research in autism: The Lancet Commission's report (Lord et al, 2022, Lancet)

Catherine Lord and Tony Charman (co-chairs)

Additional committee members & authors: Alexandra Havdahl, Paul Carbone, Evdokia Anagnostou, Brian Boyd, Gauri Divan, Christine Freitag, Marina Gotelli, Connie Kasari, Martin Knapp, Peter Mundy, Alex Plank, Lawrence Scahill, Chiara Serveli, Paul Shattuck, Emily Simonoff, Alison Singer, Vicki Slonims, Paul Wang, Cecilica Ysraelit, Rachael Jellett, Andrew Pickles, James Cusack, Patricia Howlin, Alison Holbrook, Christina Toolan, and James McCauley



Committee Composition and *some* Conclusions

- Members from six continents, 13 disciplines and 32 people, including autistic people and parents of autistic people
- First point is urgency: It is time to directly address ways of improving the lives of the 78 million autistic people in the world and their families
- There is much evidence and scientific data known about autism that is ready to be used ...
- Particularly if we can determine what strategies and interventions and support systems benefit whom, when, and with what intensity (as well as how)

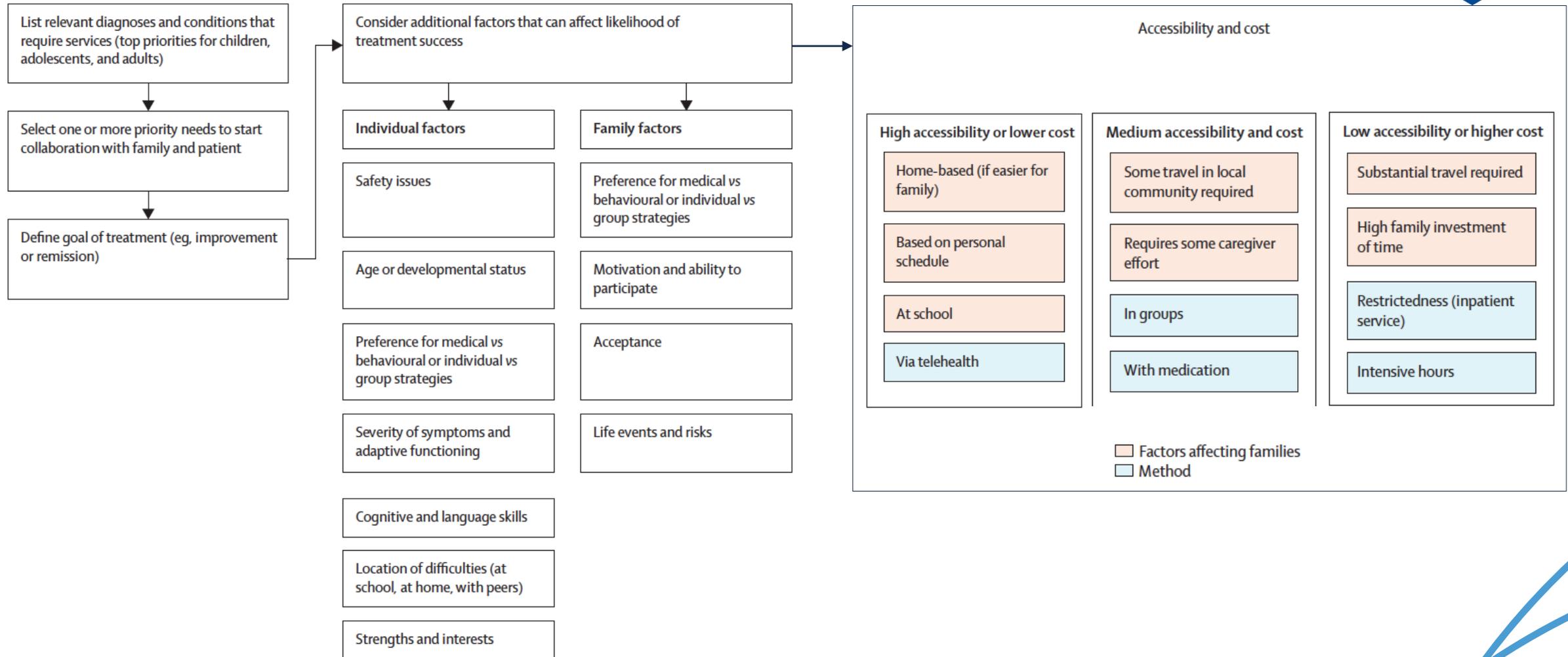


Moving to Personalized Interventions

- Committee proposed steps that take into account the **costs, burden, and preferences** of individuals or families (rather than just to the health system) and **personalization** on the basis of the autistic individual and families' needs, strengths, and challenges.
- This means that information must be gathered about the skills and needs of each autistic person and their family, beyond a diagnosis, to include other factors and preferences ...
- And updated as needed because it will change as children become adults and as adults grow older.

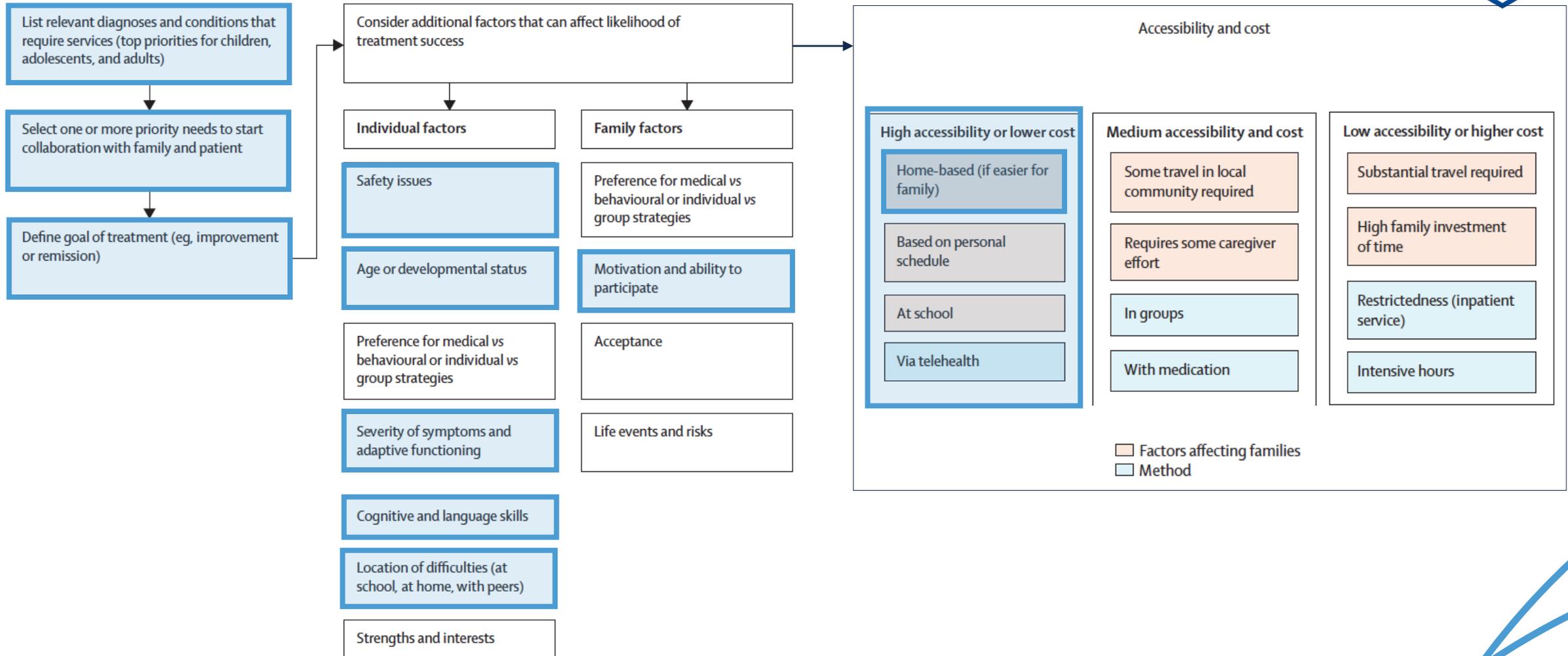


Stepped care, personalised health in autism



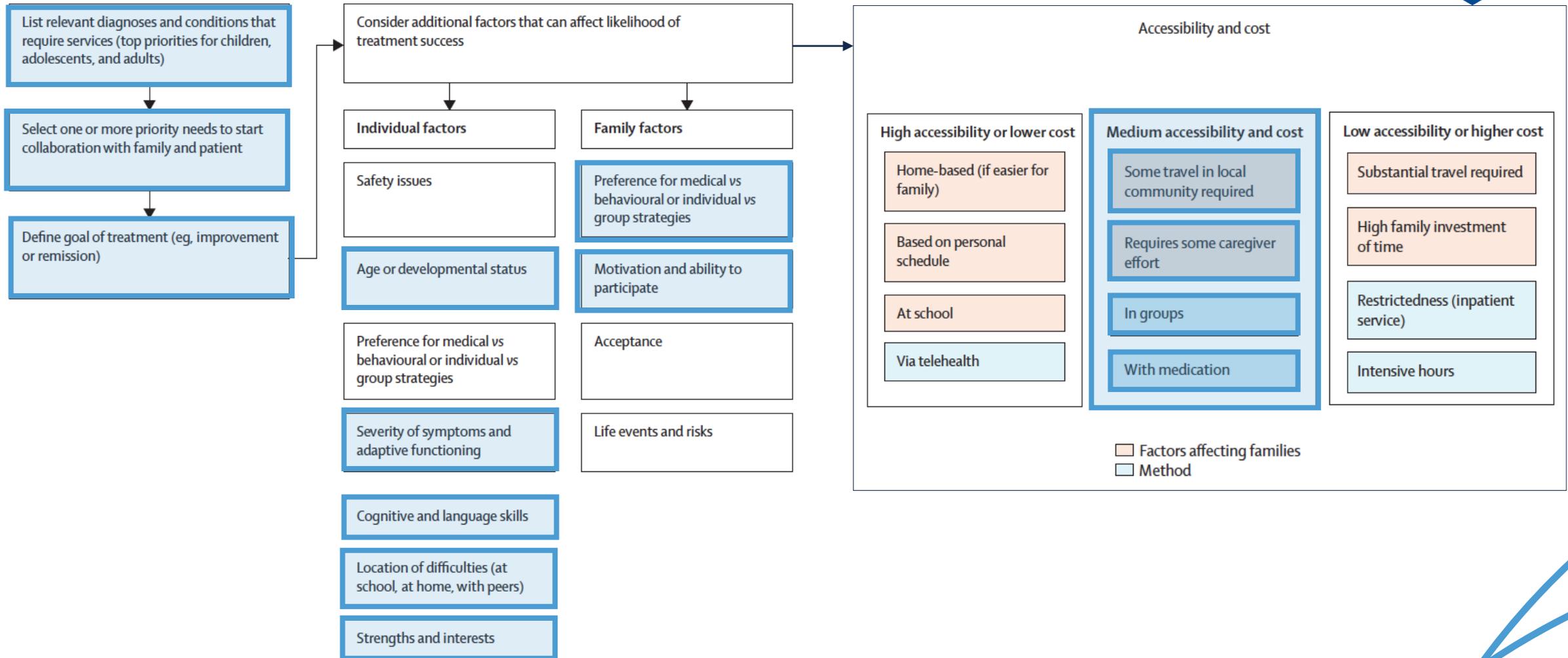


Stepped care example – minimally verbal 5 year old in LMIC





Stepped care example – 15 year old with social anxiety in **HIC**



Summary of EPB literature

- A robust suite of evidence-based practices exist for certain age ranges.
- Groups are working on methods to better disseminate and enhance professional development.
- There is still a need to support more personalization of interventions.

Evidence-base for Whom?

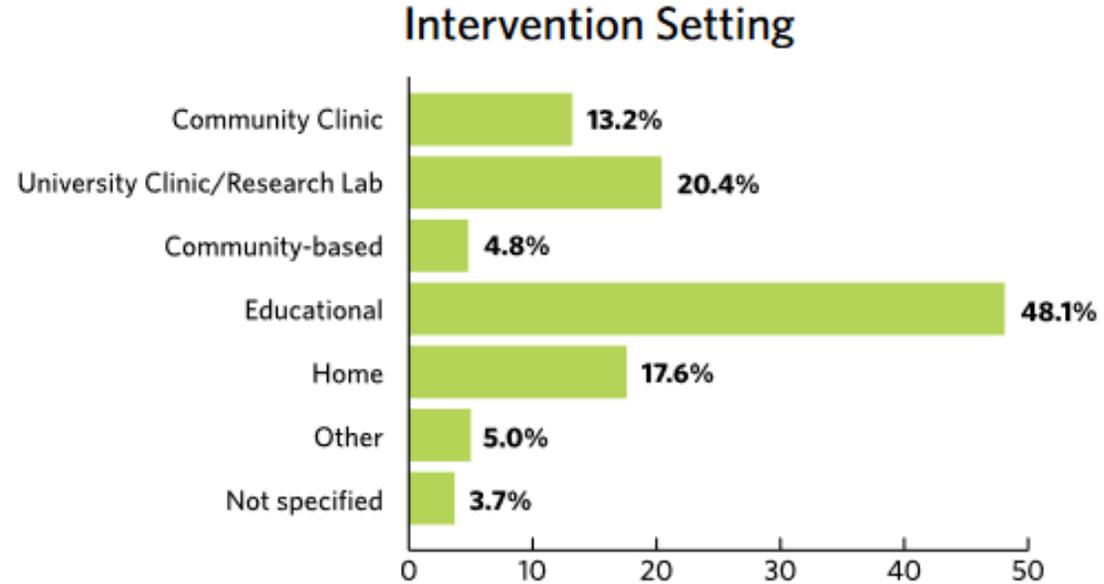
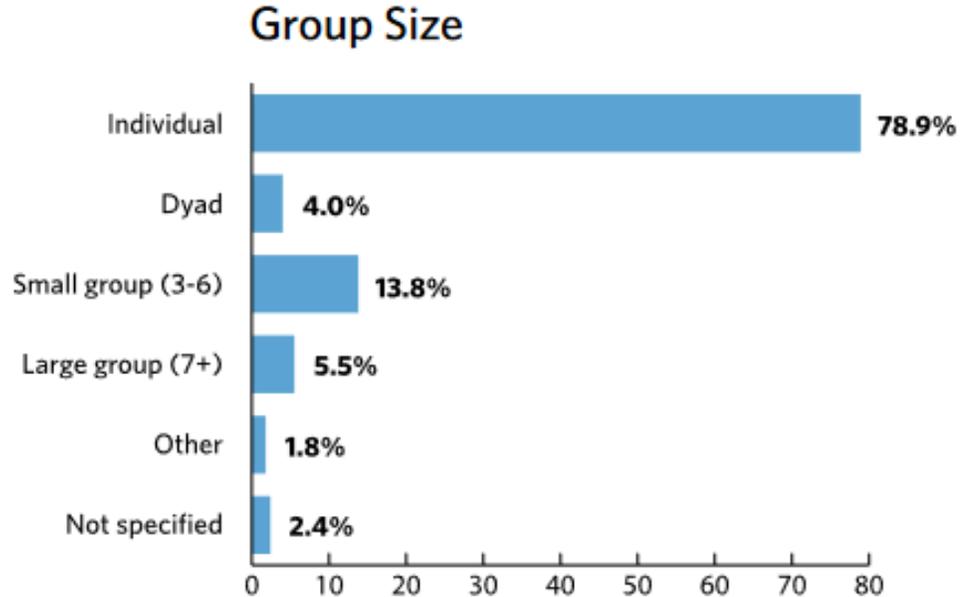


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Profound Autism

- To highlight the needs of autistic people with severe intellectual and communication disabilities with profound needs for care and support
 - Those who cannot speak for themselves and need extensive care throughout their lives
 - Require 24-hour access to an adult who can care for them if concerns arise
 - Are not able to take care of basic adaptive daily needs
- Individuals with substantial intellectual disability (IQ <50) or very limited expressive communication (or both)
 - Most have complex co-occurring difficulties e.g., self-injury, epilepsy, aggression
 - Appropriate to identify from mid-childhood or later when future needs are clear
- Intended to spur the clinical and research communities to prioritize the needs of this vulnerable and underserved group of autistic individuals

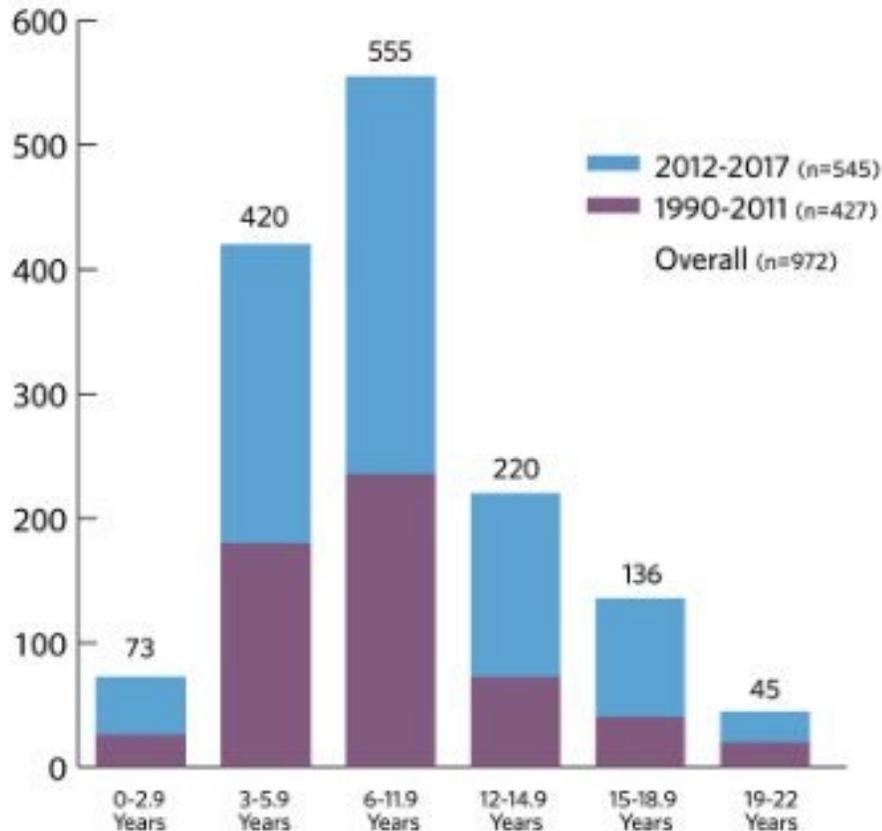
Limitations in the Studies



- Adults (from young to older) are severely underrepresented in research
- Many studies do not include measures of social validity from autistic participants
- Many studies do not include adverse event/side effect information

Limitations in the Studies

Figure 3.4 Age of participants across review periods



Steinbrenner et al., 2020

Table 3.4 Race/ethnicity/nationality and gender/sex of participants in 2012-2017 review period

Gender/Sex	2012-2017	
	Articles (n=545)	Participants
Male	485	5934
Female	259	1097
Not reported	38	
Total		7031
Race/Ethnicity/Nationality		
African American/Black	74	343
Asian	52	314
Hispanic/Latino	52	281
Middle Eastern	9	45
Native American	1	1
Native Hawaiian/Pacific Islander	3	3
White	130	2101
Two or more/Multi-racial	24	119
Other	29	257
Not specified	7	88
Not reported	381	
Total		3552

Parental Perspective



Where Do We Go Next?



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Why do community work?

“

Of all the forms of inequality, injustice in health care is the most shocking and inhumane.

~Dr. Martin Luther King, Jr.



Barriers to Engaging Racial/Ethnic Minority Families in research

- Distrust toward research
- Language barriers
- Cultural barriers / stigma
- Unfamiliarity with research

Equity-informed Community Engaged Research

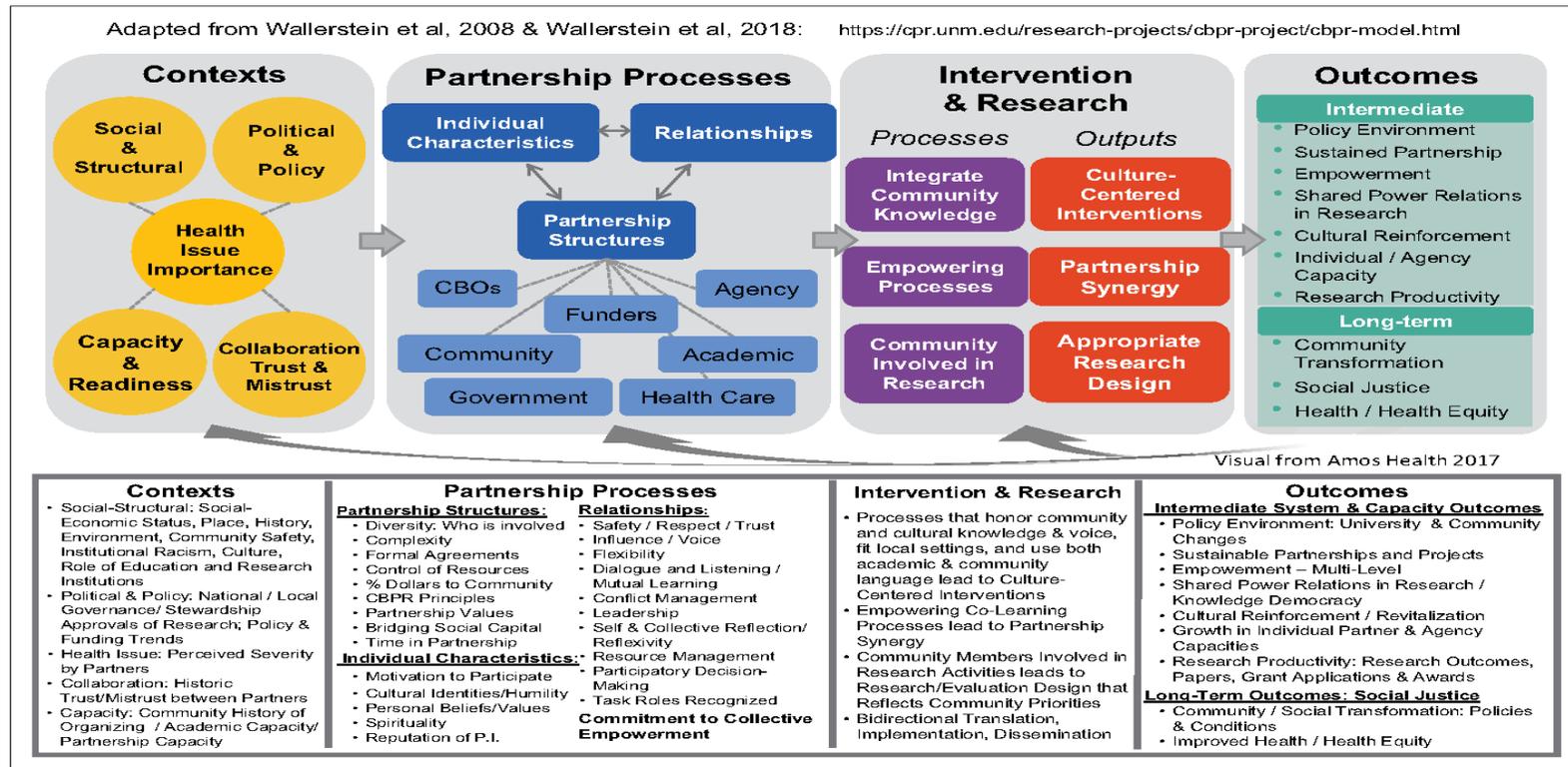


Figure 1. Community-based participatory research conceptual model.
 Note. CBOs = community-based organizations; CBPR = community-based participatory research; P.I. = principal investigator.

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Health Education & Behavior 47(3)

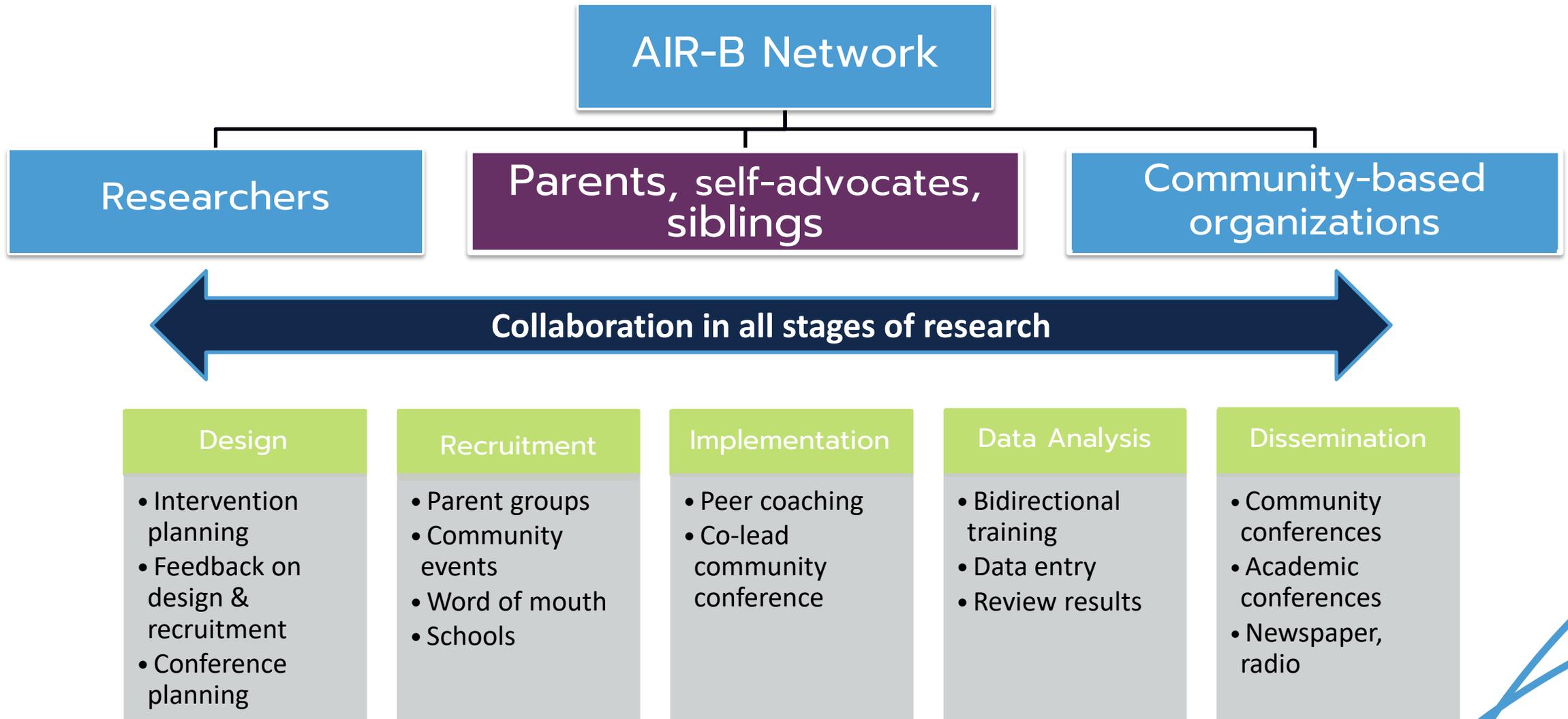
CER Recommendations

- Engage in self-reflection and seek supports to develop cultural humility.
- Reflect on one's own identities and biases and how they do (not) align with the community partners.
- Reflect on one's motivation for conducting the research and working with a community group.
- Cultivate a culturally sensitive and diverse team.
- Foster an inclusive climate and beware of tokenism.

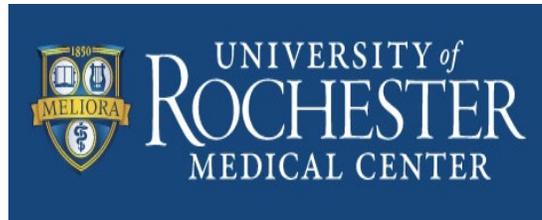
Maye, M., Boyd, B. A., Martínez-Pedraza, F., Halladay, A., Thurm, A., & Mandell, D. S. (2021). Biases, barriers, and possible solutions: Steps towards addressing autism researchers under-engagement with racially, ethnically, and socioeconomically diverse communities. *Journal of autism and developmental disorders*, 1-6.



Academic & Community Partners Working Together



Participating sites





<https://youtu.be/H5uME6bMxVY>

Many Evidence-Based Practices



National Standards Report

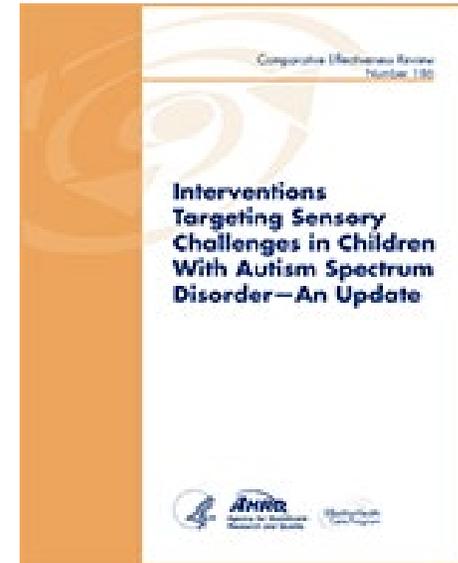


THE NATIONAL STANDARDS PROJECT—
ADDRESSING THE NEED FOR EVIDENCE-
BASED PRACTICE GUIDELINES FOR
AUTISM SPECTRUM DISORDERS

A Systematic Review of Vocational Interventions for Young Adults With Autism Spectrum Disorders

AUTHORS: Julie Lounds Taylor, PhD,^a Melissa L. McPheeters, PhD, MPH,^{b,c} Nila A. Sathe, MA, MLIS,^c Dwayne Dove, MD, PhD,^a Jeremy Veenstra-VanderWeele, MD,^d and Zachary Warren, PhD^{a,e}

abstract
BACKGROUND AND OBJECTIVE: Many individuals with autism spectrum disorder (ASD) are unprepared, uneducated, and young adults



But they don't get used, especially in under-resourced settings

Implementation-as-Usual in Community-Based Organizations Providing Specialized Services to Individuals with Autism Spectrum Disorder: A Mixed Methods Study

Amy Drahota^{1,2}  · Rosemary D. Meza³ · Tatiana E. Bustos¹ · Aksheya Sridhar¹ · Jonathan I. Martinez⁴ · Brigitte Brikho² · Aubyn C. Stahmer^{2,5} · Gregory A. Aarons^{2,6}

Does implementing a new intervention disrupt use of existing evidence-based autism interventions?

Melanie Pellecchia¹ , Rinad S Beidas¹, Gwendolyn Lawson¹, Nathaniel J Williams², Max Seidman¹, John R Kimberly¹, Carolyn C Cannuscio¹ and David S Mandell¹

Dismantling the Active Ingredients of an Intervention for Children with Autism

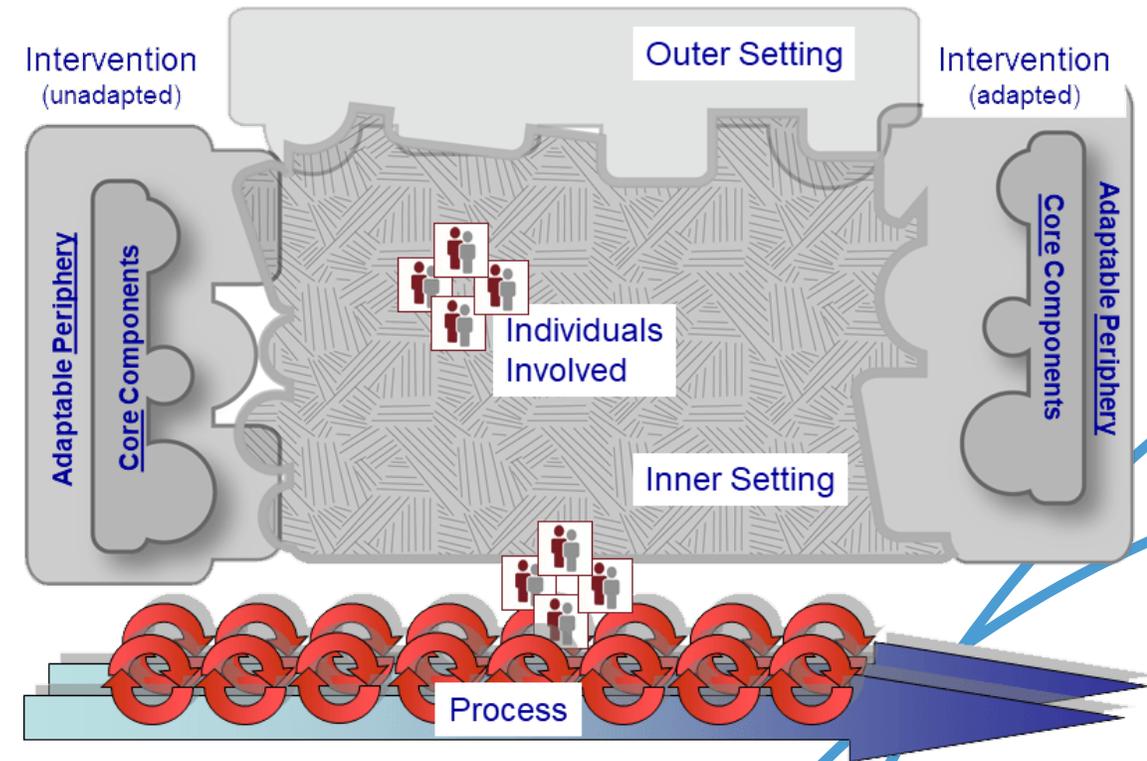
Melanie Pellecchia¹ · James E. Connell² · Rinad S. Beidas¹ · Ming Xie¹ · Steven C. Marcus¹ · David S. Mandell¹

Implementation science offers models and strategies, but they are often complex and intervention specific

A refined compilation of implementation strategies: results from the Expert Recommendations for Implementing Change (ERIC) project

Byron J Powell^{1*}, Thomas J Waltz², Matthew J Chinman^{3,4}, Laura J Damschroder⁵, Jeffrey L Smith⁶, Monica M Matthieu^{6,7}, Enola K Proctor⁸ and JoAnn E Kirchner^{6,9}

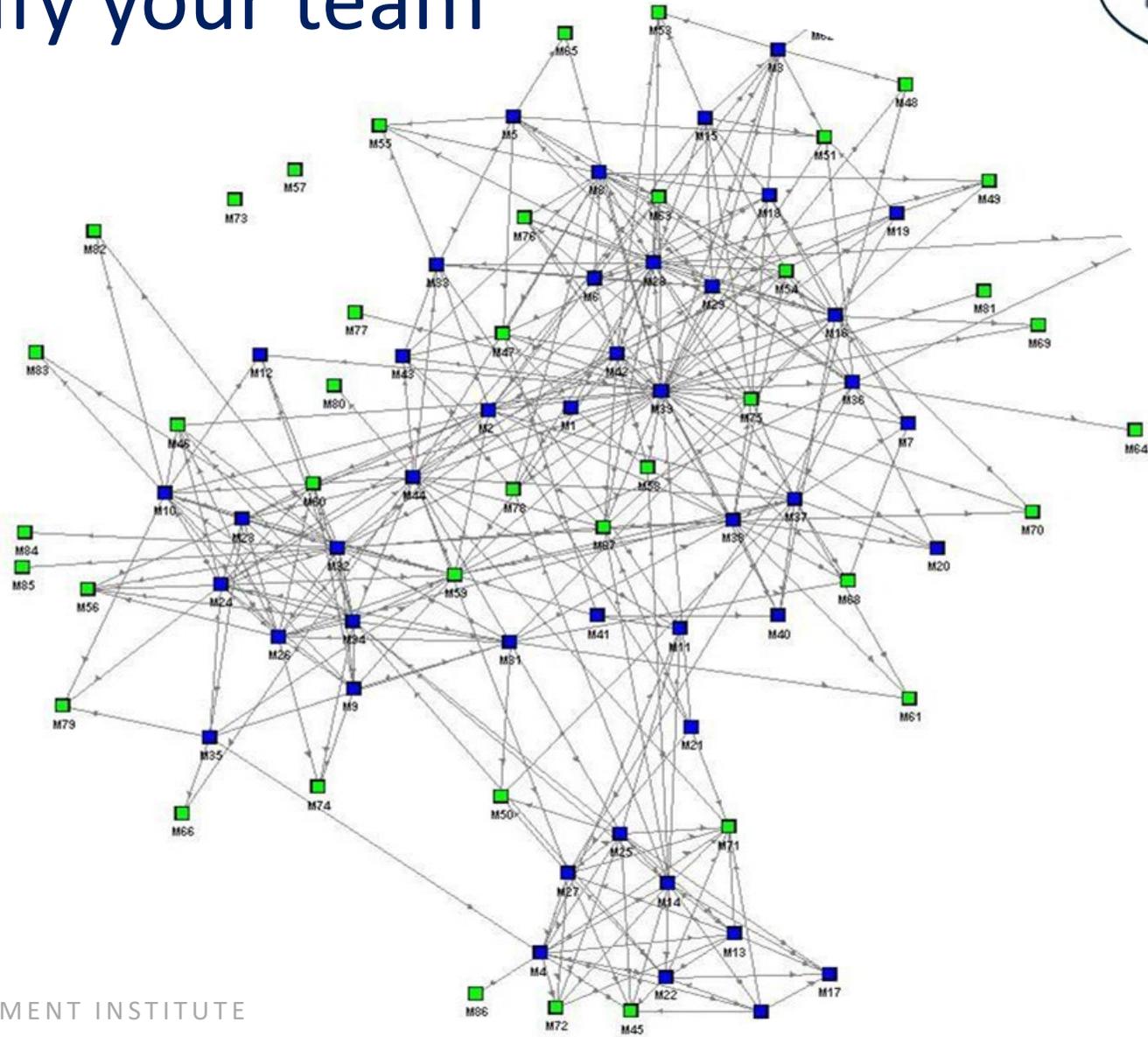
...and who's got time for that?



Using Novel Implementation Tools for EBI Delivery

- Identify your team
- Establish goals and objectives
- Create communication plan
- Create measurement plan
- Create feedback plan
- Brief weekly check-in with team leader
- Brief monthly meeting with team

Identify your team



First Team Meeting

- Review the UNITED intervention and logistics.
- Review collaborative teaming.
- Review the results of your social network survey.
- Identify potential UNITED team members.
- Establish guidelines for future meetings (roles and norms).
- Introduce the UNITED implementation action plan to support intervention.
- Discuss next steps and resources needed to implement intervention.

Second Team Meeting

- Introduce the UNITED Intervention.
- Confirm ground rules and roles for the implementation team.
- Identify implementation goals and develop an action plan.
- Establish guidelines for communication between meetings.
- Establish ongoing meeting schedule.

Weekly Check-Ins and Monthly Meetings

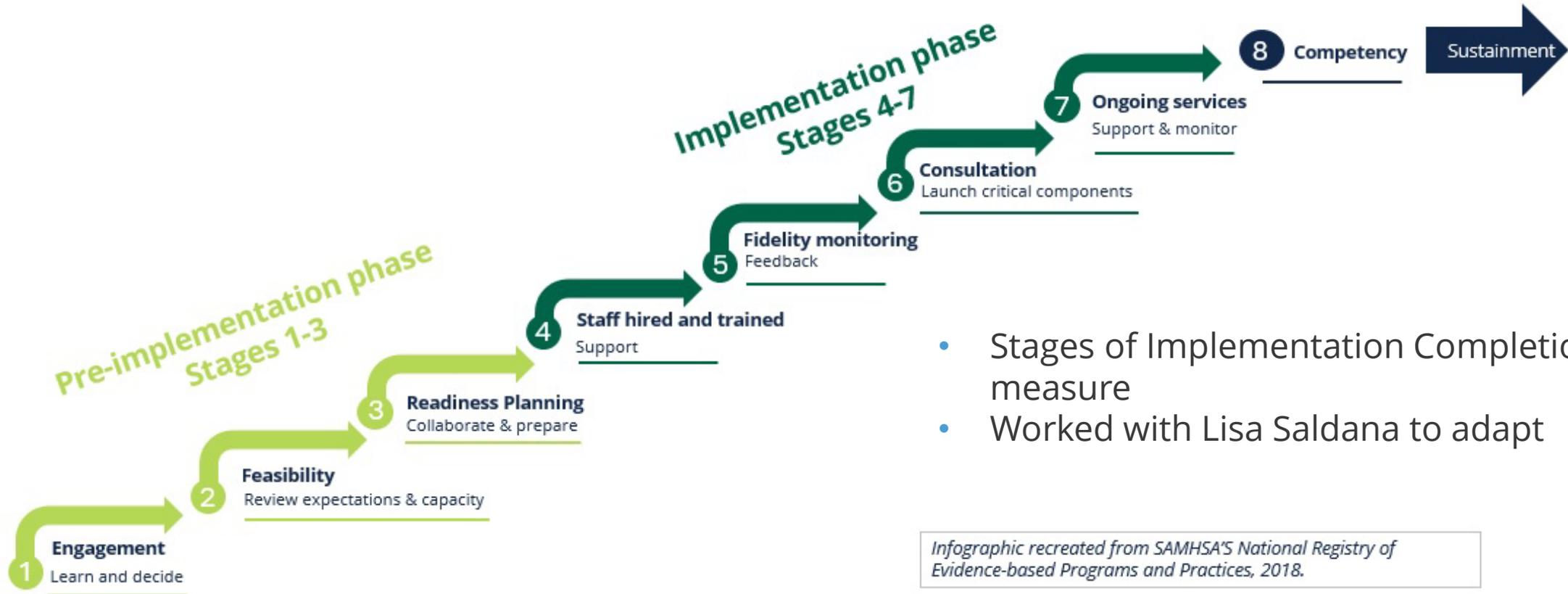
Weekly Check-ins

- With Facilitator in Training via email or text
- Brief check-in to see how things are going and offer troubleshooting as needed

Monthly Meetings

- With implementation team
- Team reports progress on completion of action task to achieve implementation goals
 - Identify any barriers and develop potential solutions
 - Re-assign task as needed

How we will know UNITED is working



Stages of Implementation Completion



All 3 studies will be randomized to have or NOT have:

UNITED

Using **N**ovel
Implementation **T**ools
For **E**vidence-Based
Intervention **D**elivery

An Evidence-based Intervention to Improve Students' Self-determination Skills



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What do we know so far?



Greater
academic
achievement

- Progress in general education curriculum
- Academic goal attainment

Increased
postsecondary
outcomes

- Postsecondary education
- Competitive, integrated employment
- Community participation
- Quality of life

- Shogren, K. A., Burke, K. M., Antosh, T., Wehmeyer, M. L., LaPlante, T., Shaw, L. A., & Raley, S. K. (2018). Impact of the Self-Determined Learning Model of Instruction on self-determination and goal attainment in adolescents with intellectual disability. *Journal of Disability Policy Studies, 30*(1), 22-34. <https://10.1177/1044207318792178>
- Shogren, K. A., Hicks, T. A., Raley, S. K., Pace, J. R., Rifenburg, G. G., Lane, K. L., & Quirk, C. (in press). Student and teacher perceptions of goal attainment during intervention with the Self-Determined Learning Model of Instruction. *The Journal of Special Education*.
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenburg, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education, 48*, 256-267.

SDLMI Overview



SDLMI enables teachers to teach students to:

- Make choices and decisions about setting a goal.
- Develop action plans for academic and transition goals.
- Self-monitor and self-evaluate progress toward goals.
- Adjust the goal or plan.



What is my goal?



Phase 1:
Set a goal

What is my plan?



Phase 2:
Take action

What have I learned?

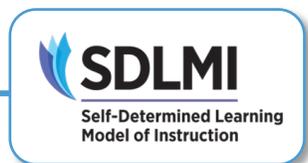


Phase 3:
Adjust goal or plan



Teacher Experience

“The commitment to self-determination is a classroom practice and a lifelong learning experience that I strive to instill in every student.”



Conclusions and Next Steps

- Our current evidence base is limited because our research has been exclusionary or overlooked certain groups.
- There is a need to partner with communities to bridge the research-to-practice gap. Implementation science and CER provide approaches for doing so.
- Moving forward, we need:
 - The inclusion of more autistic individuals and other marginalized communities as co-producers of research.
 - Additional information about the potential harms associated with research.
 - Research across the lifespan.

Acknowledgements



Connie Kasari
(AIRB)



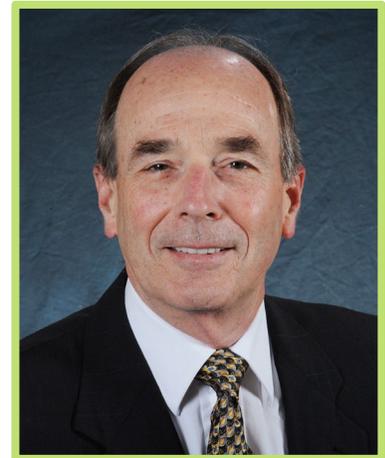
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(Lancet)



Karrie Shogren
(SDLMI)



Ann Sam
(NCAEP)



Sam Odom
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