Parent Training for Autistic Youth with Challenging Behaviors: An Overview of the RUBI Parent Training Program

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Disclosures

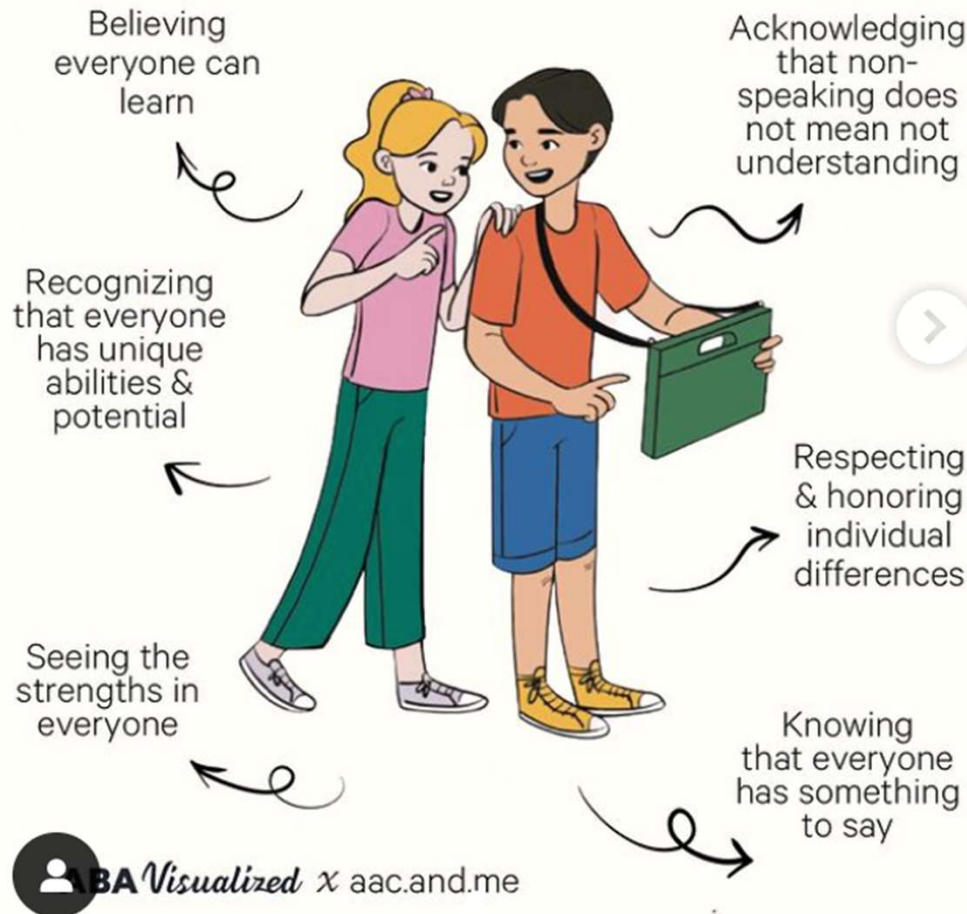- Royalties from Oxford University Press

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Learning Objectives

1) Describe the role of parent training as part of a comprehensive treatment model for autistic youth

2) Discuss the research base and content of the RUBI Parent Training program, including target clinical populations appropriate for the delivery of RUBI

3) Compare various treatment models appropriate for community-based delivery of RUBI that are designed to increase access to care

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A Note About Language

- I will primarily use **identity first** language ("autistic child") to honor the preference of many autistic advocates

- This is in contrast to **person first** language ("child with autism")

- In clinical practice, we ask the individual on the spectrum (or their caregiver) about their preferences

APA, 2020; Bottema-Beutelet al., 2020; Bury et al., 2020; Kenny et al., 2016

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What does it mean to *Presume competence?*

Believing everyone can learn

Acknowledging that non-speaking does not mean not understanding

Recognizing that everyone has unique abilities & potential

Respecting & honoring individual differences

Seeing the strengths in everyone

Knowing that everyone has something to say

ABA *Visualized* x aac.and.me

Janna Bedoyan & ABA Visualized, 2024

Shared by a RUBI practicum student

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Good News, Bad News

Good News

- Better at diagnosing autism
  - Prevalence at 1 in 36 (CDC, 2023)

Bad News
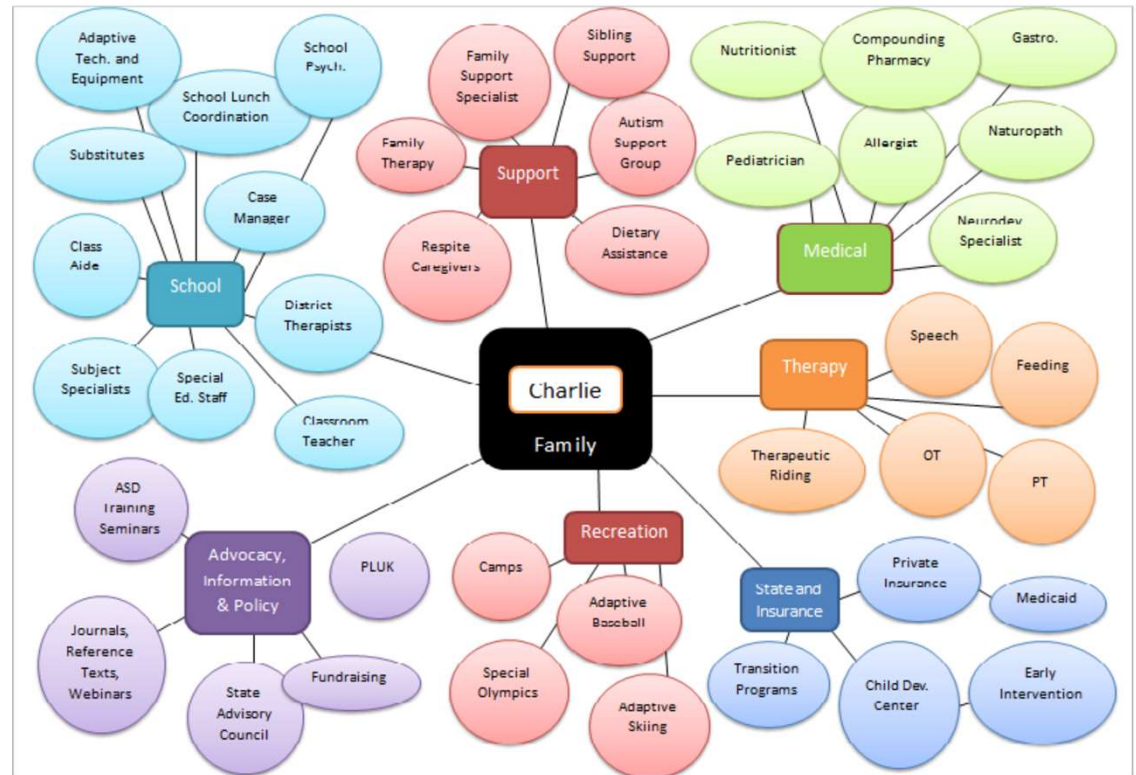
- Limited access to evidence-based treatments (ABA)
  - Time and personnel intensive
  - Challenges to wide-ranging dissemination

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Added Challenges of Treatment

Parents of autistic youth juggle multiple, fragmented appointments

-Average 4-7 different treatments at any one time

- > severity of symptoms, the more treatments in use (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006)
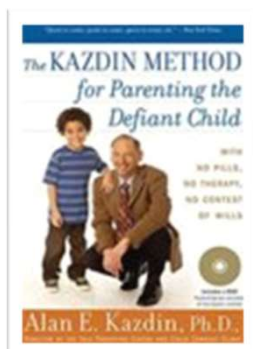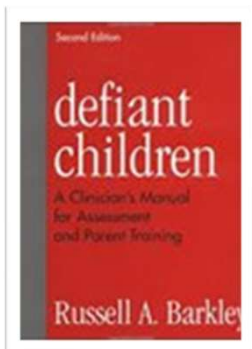

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There is a pressing need to expand the availability of treatments for autistic individuals that are: **empirically supported**, **time-limited**, **cost-effective**

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Parent Training

- Traditionally a time-limited approach

  o Few hours per week

- Emphasizes role of parents as the agent of change

- History as established EBT in child mental health

Why Target Parents of Autistic Youth?

- High rate of Quality of Life-interfering behaviors (≈50%)

- Impact on adaptive skills

- High parent stress/accommodation

- Parents want (good) parent training

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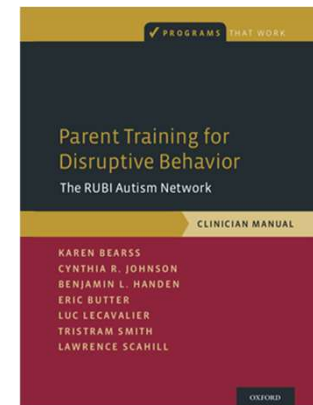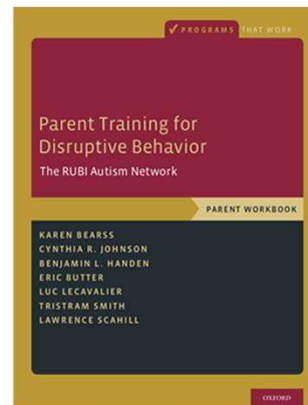CATALIGHT

RUBI Parent Training Program

11 Core Sessions

- Behavioral Principles (the ABC's)
- Prevention Strategies
- Daily Schedules
- Reinforcement 1 & 2
- Mindful Attention
- Following Instructions
- Functional Communication Skills
- Teaching Skills 1 & 2
- Generalization & Maintenance
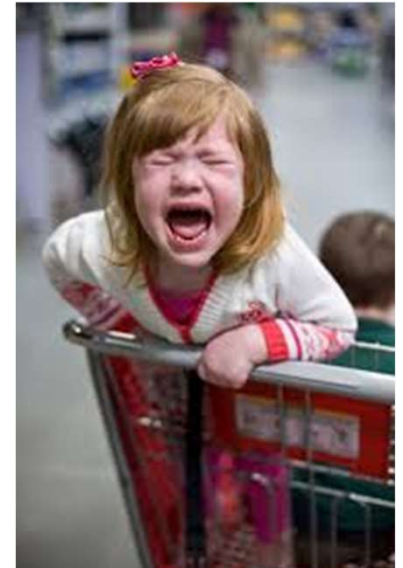
- **PLUS**
- Home Visits
- Telephone Boosters

7 Supplemental Sessions

- Toileting
- Feeding
- Sleep
- Time Out
- Imitation
- Crisis Management
- Token Economies

RUBI Intervention Targets

- Reduce challenging behaviors
  - Meltdowns, aggression, transition difficulties

- Increase adaptive skills

Guiding Principle of RUBI

**Understanding Challenging Behaviors
Through The Lens of Autism**

Behavior is communication

Autism presentation

Receptive/expressive language vulnerabilities	Rigidities (can't vs won't)	Sensory sensitivities	Fine/gross motor skill vulnerabilities	Literal/linear thinking	Strengths in visual processing	Common co-occurring conditions: ADHD, anxiety

With this in mind, and understanding autism, what are possible alternative explanations for "defiant", "noncompliant" and other "challenging" behaviors?

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The Goal of RUBI

WHAT BEHAVIOR ARE WE TARGETING? (clear descriptions/ behavioral terms; What are antecedents to this behavior? What about setting events? What is the consequence?)	
WHAT IS THE FUNCTION OF THE BEHAVIOR? (What is the child trying to communicate through this behavior?)	
CAN WE PREVENT THE BEHAVIOR FROM HAPPENING? (Reference 8 prevention strategies, visual supports or changes to daily schedules)	
CAN WE CHANGE THE RESPONSE TO THE BEHAVIOR? (Think reinforcement, mindful attention, following instructions)	
CAN WE TEACH A NEW SKILL TO REPLACE THE BEHAVIOR? (Think functional communication, teaching skills, or possible referral (OT/Speech)	
WHAT WILL PRACTICE LOOK LIKE? (targeted times, situations)	

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Prototypical RUBI Clinic Case

3-14* years old

- Mild to moderate challenging behaviors
  - Meltdowns, aggression, transition difficulties, mild SIB, inappropriate language

This is all good...

- Identified caregiver who can regularly attend
- Broad range of autism severity and cognitive functioning
  - Consider 12-18 month receptive language criteria

Exclusionary criteria

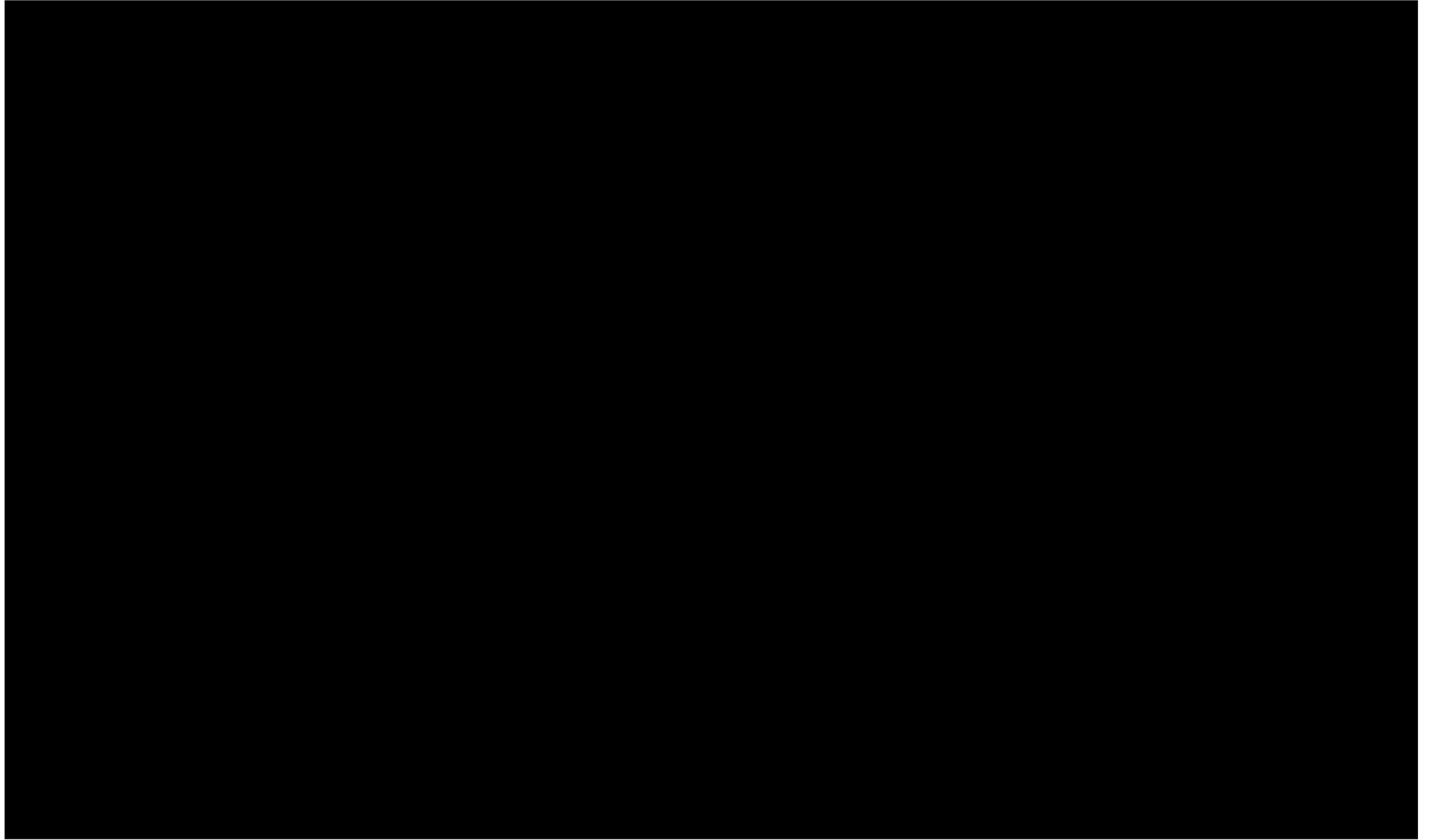- Focal issues (e.g. pica, elopement, encopresis)
- Behaviors resulting in hospitalization or tissue damage (self or others)

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RUBI Program

- Delivered individually

- Structured Program Materials
  - Clinician Manual
    - Session Scripts
    - Fidelity Sheets

  - Parent Workbook
    - Activity Sheets
    - Video Vignettes
    - Homework data sheets
    - Summary Handout

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Behavior Support Plan (BSP)

- An organizing and living document
  - summarizes various intervention strategies that were devised and implemented for each child

- Introduced Session 1 & updated in subsequent sessions

- Serves as a final summary of accomplishments, challenges, and solutions
  - Finalized at last session

The Art of Treatment

Principles

- Expert guided
- Family-centered
- Partnering
(co-construction)

Promotes

knowledge transfer

meaningful targets

new skills

behavior change

You don't have to have all the answers.
Your job is to guide the parent in
coming up with their own answers
(which will generally be better anyway…)

Neurodiversity-Affirming Framework

"The extent to which *differences* constitute *impairments,* which can, in turn, be *disabling* requires reference to the *supports* that are provided (or not) in particular *environments* and the *sociocultural contexts* in which particular abilities are valued or not."

Bottema-Buetel et al., 2021

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RUBI in the Context of the Neurodiversity Movement

- Ensuring RUBI:
  - Looks beyond observable behaviors to sensory/emotional experiences of neurodivergent individuals
  - Honors self-regulatory behaviors
  - Targets external/environmental causes of distress
  - Works to improve goodness of fit between child and physical/social environment
  - Builds effective communication between child and others
    - Double empathy problem = Learn to "speak the child's language"
  - Promotes opportunities for autonomy, agency, and improved quality of life

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Original Investigation

Effect of Parent Training vs Parent Education on Behavioral Problems in Children With Autism Spectrum Disorder
A Randomized Clinical Trial

Karen Bearss, PhD; Cynthia Johnson, PhD; Tristram Smith, PhD; Luc Lecavalier, PhD; Naomi Swiezy, PhD; Michael Aman, PhD; David B. McAdam, PhD; Eric Butter, PhD; Charmaine Stillitano, MSW; Noha Minshawi, PhD; Denis G. Sukhodolsky, PhD; Daniel W. Mruzek, PhD; Kylan Turner, PhD; Tiffany Neal, PhD; Victoria Hallett, PhD; James A. Mulick, PhD; Bryson Green, MS; Benjamin Handen, PhD; Yanhong Deng, MPH; James Dziura, PhD; Lawrence Scahill, MSN, PhD

JAMA The Journal of the American Medical Association

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CLINICAL PATHWAYS AND TOOLS
for optimizing care and outcomes for children with autism spectrum disorder (ASD)

Advancing care together.
autism care network
autism speaks

2024

Clinical Pathway for Co-Occurring Irritability & ASD
APPENDIX

OPERATIONAL DEFINITION FOR CLINICAL DETERMINATION OF IRRITABILITY FOR PURPOSES OF ACNET DATA COLLECTION AND ANALYSIS

- Presence of the following behaviors: frequent mood changes (mood lability), tantrums, aggression, self-injury.
- Description in the clinical note of the patient being "irritable" as a symptom feature.
- Irritability could (but does NOT need to) include a diagnosis of: Disruptive Mood Dysregulation Disorder (DMDD), Bipolar Disorder, Intermittent Explosive Disorder (IED), Major Depressive Disorder.
- Use of a medication commonly used to treat irritability in individuals with autism, such as atypical antipsychotics: Aripiprzole (Abilify), Risperidone (Risperdal).

PSYCHOSOCIAL TREATMENT TO INCREASE POSITIVE BEHAVIORS AND DECREASE CHALLENGING BEHAVIORS

Therapies promoting communication and social skills:

- Discrete Trial Training
- Incidental Teaching, Pivotal Response Training, Early Start Denver Model (and others)
- Applied Behavior Analysis (ABA) to target specific problems: sleep, toileting, self-injurious behaviors

Therapies focusing on increasing compliance and decreasing challenging behaviors:

- RUBI Parent Training
- Parent Child Interaction Therapy (and others)
- Triple P
- Stepping Stones
- ABA
- Caregiver Skills Training (CST) and eLearning CST (eCST), Family ECHO

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THE CALIFORNIA EVIDENCE-BASED
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FOR CHILD WELFARE
Information and Resources for Child Welfare Professionals

Home | Program Registry | Implementation | Find Programs
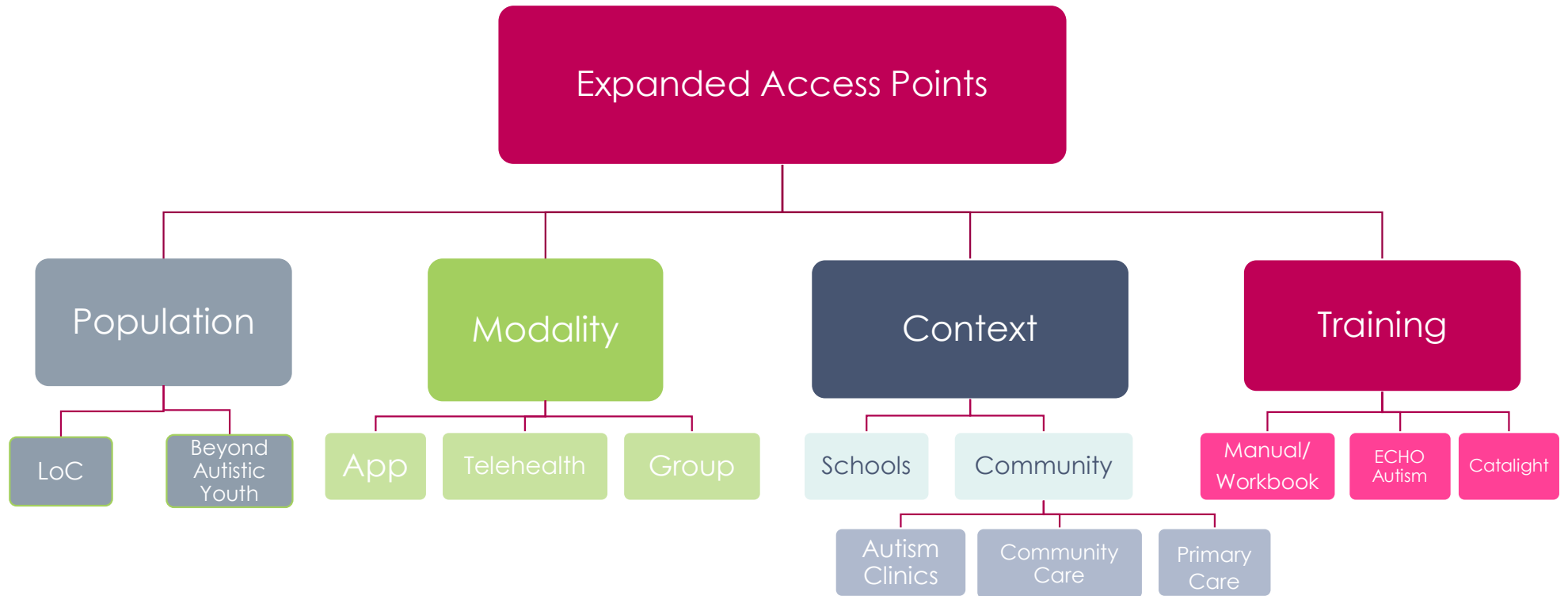
Programs | Topic Areas | Rating Scales

Home ‹ Program ‹

RUBI Parent Training (RUBI-PT)

Topic Areas	Scientific Rating	Child Welfare Relevance
Developmental and Autism Spectrum Disorder Interventions (Child & Adolescent)	2 — Supported by Research Evidence	Medium

compare (?)

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RUBI Dissemination/Implementation Targets

Expanded Access Points

- **Population**
  - LoC
  - Beyond Autistic Youth
- **Modality**
  - App
  - Telehealth
  - Group
- **Context**
  - Schools
  - Community
    - Autism Clinics
    - Community Care
    - Primary Care
- **Training**
  - Manual/Workbook
  - ECHO Autism
  - Catalight

RUBI Dissemination/Implementation Targets

Clinical Populations

Language of Care

Beyond Autistic Youth

Autistic Adults

Other Neurodevelopmental Conditions

Home > Journal of Autism and Developmental Disorders > Article

From Clinic Room to Zoom: Delivery of an Evidence-Based, Parent-mediated Intervention in the Community Before and During the Pandemic

S.I.:Expanding Telehealth Opportunities in Neurodevelopmental Disorders | Published: 28 June 2022

Volume 52, pages 5222–5231, (2022)   Cite this article

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Tobi Graucher, Yana Sinai-Gavrilov, Yaniv Mor, Shay Netzer[1], Eyal Y. Cohen, Linoy Levi, Tzlil Birenboim Avtalion & Judah Koller ✉

자폐증의 문제행동에 대한 부모훈련

Parent Training for Disruptive Behavior
The RUBI Autism Network

THE UNIVERSITY OF UTAH SCHOOL PSYCHOLOGY
U-TTEC Lab   The **RUBI** Autism Network
Building evidence-based tools for ASD
APBS

O AR — ORGANIZATION FOR AUTISM RESEARCH

EAGLES AUTISM FOUNDATION
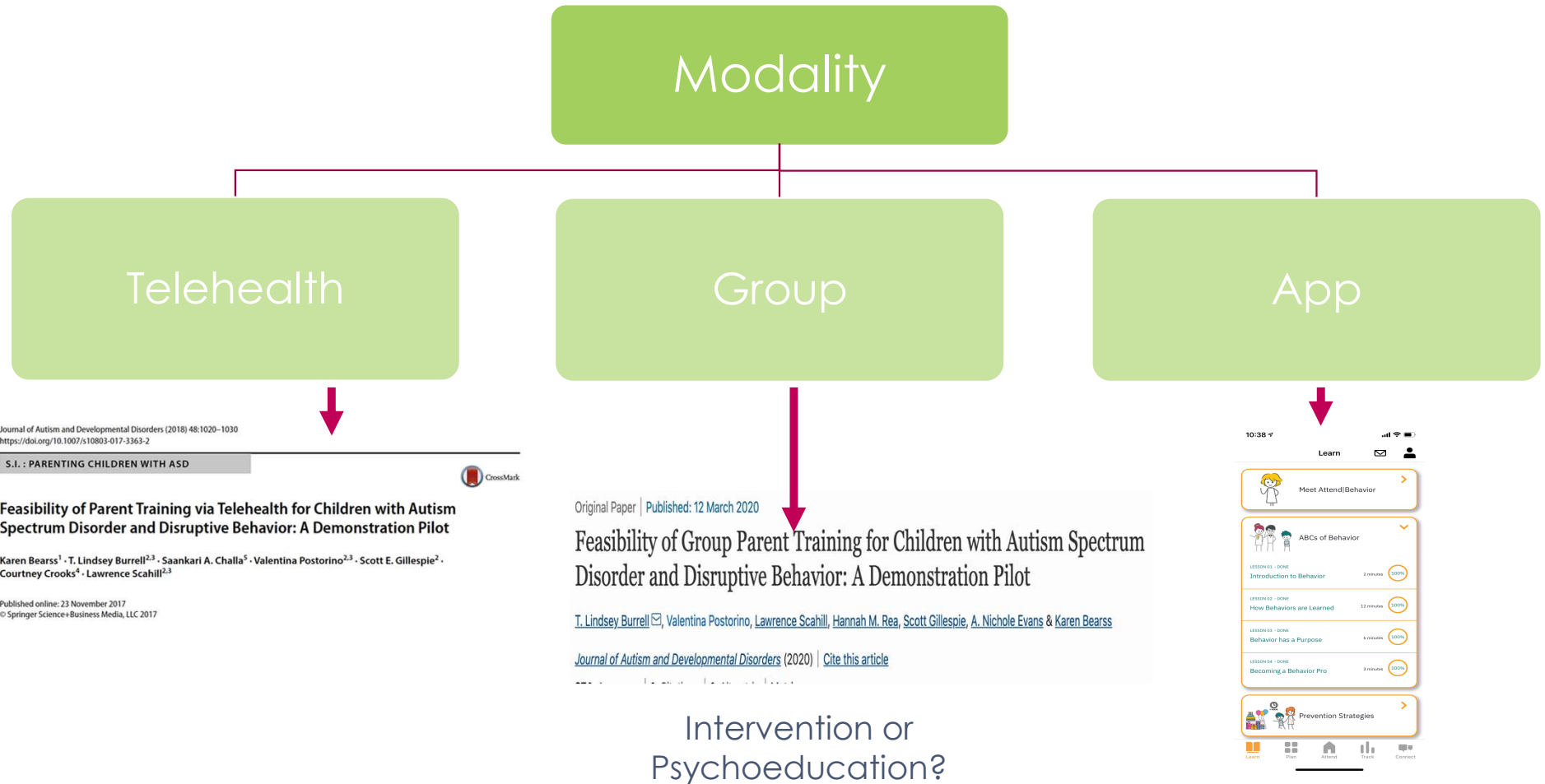
An Intervention Program for Families of Adults on the Autism Spectrum: A Case Study

Daina M. Tagavi ✉ ✉, Gary A. Stobbe, and Karen Bearss View all authors and affiliations

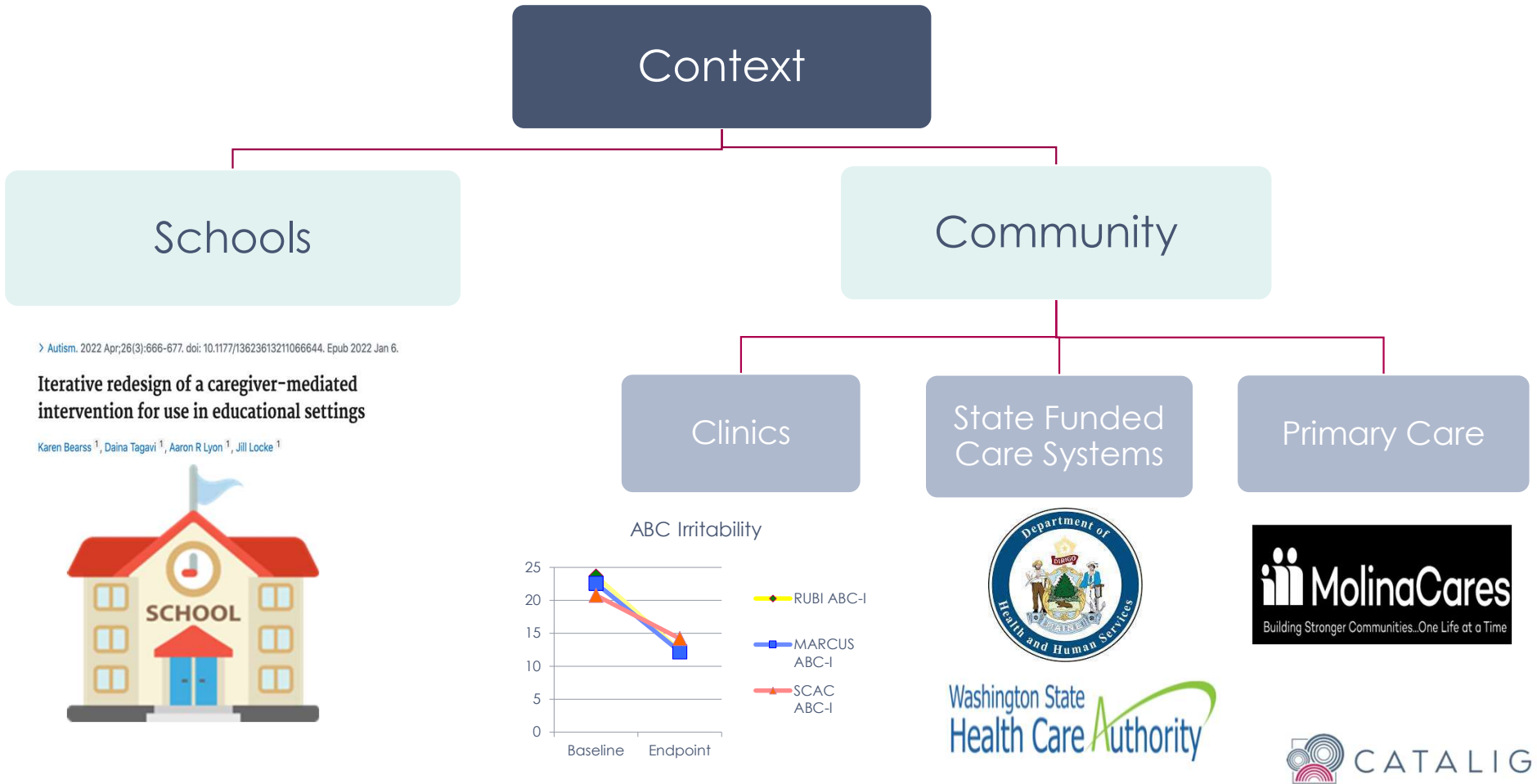Volume 23, Issue 1 | https://doi.org/10.1177/15346501231170149

▸ J Clin Psychol Med Settings. 2023 Feb 25:1–10. Online ahead of print. doi: 10.1007/s10880-023-09949-1 ☑

The RUBI Parent Training for Disruptive Behavior in a Child with Electrical Status Epilepticus in Sleep (ESES): A Case Report

Emily R Jellinek[1][✉], Thomas A Duda[2], Rachel H Fein[2]

Randomized Controlled Trial   › J Intellect Disabil Res. 2024 Sep;68(9):1077-1086.
doi: 10.1111/jir.13171. Epub 2024 Jul 9.

Feasibility study of a parent-driven intervention for youth with Down syndrome

M Stone-Heaberlin[1][2], A Blackburn[1][2], E K Hoffman[3], A J Esbensen[1][3]
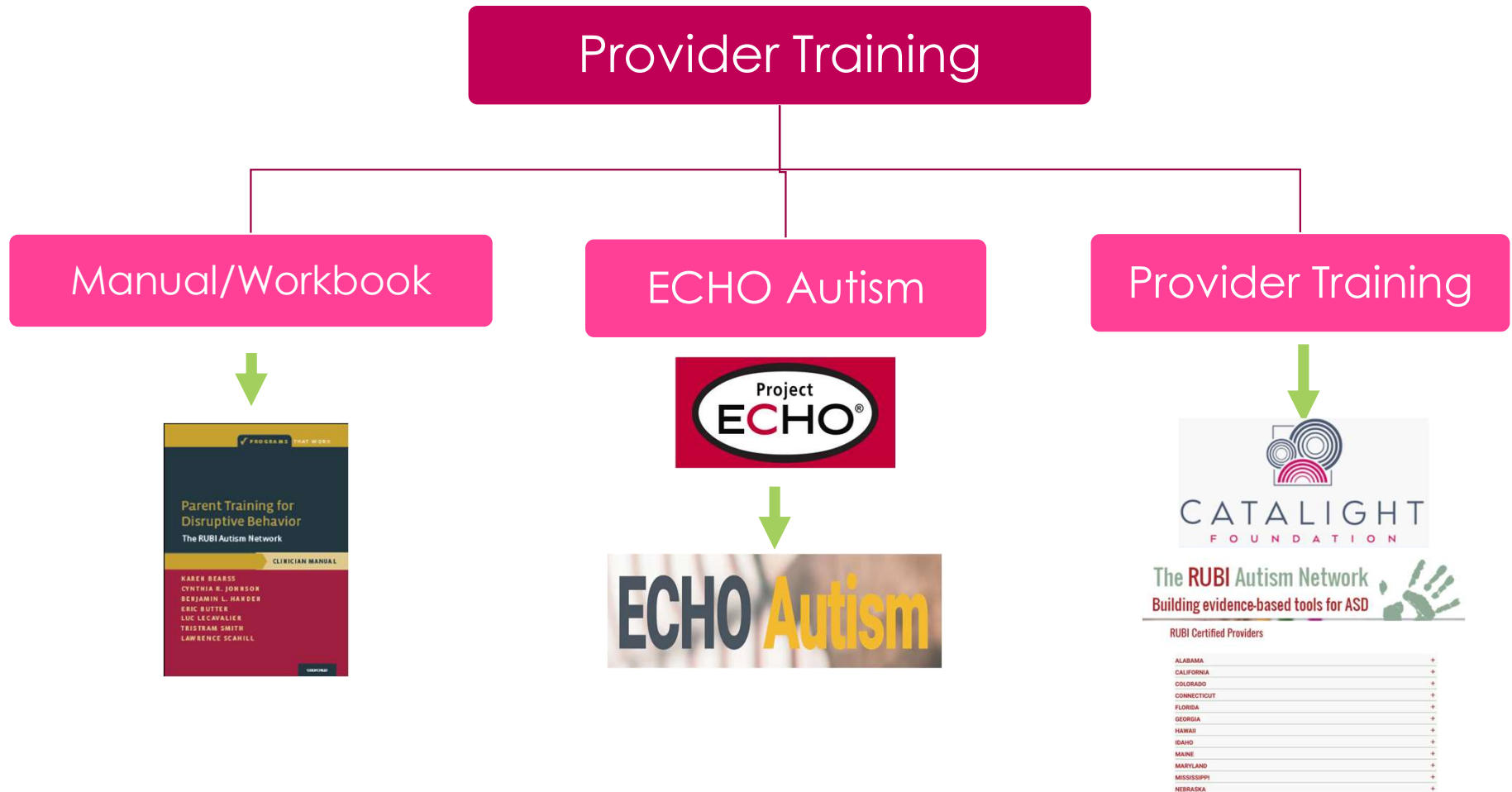
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RUBI Dissemination/Implementation Targets

RUBI Dissemination/Implementation Targets

RUBI Dissemination/Implementation Targets

RUBI Take Home

- Low-intensity evidence-based program
  - Responsive to access issues

- Structured/manualized intervention
  - Understanding behaviors through the lens of autism

- Flexible implementation with lifespan potential
  - Group/individual; clinic/telehealth; home/school

- Training-friendly model that supports implementation by providers from varied backgrounds
  - PhD, LMHC, Psychiatry, BCBA, ARNP, SLP

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Resources and training for professionals working in the field of intellectual and developmental disabilities, including autism.

Thank You

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