



Addressing Mental Health in Teens with FASD:

*Building Accessible and Community-Informed
Treatment Approaches*

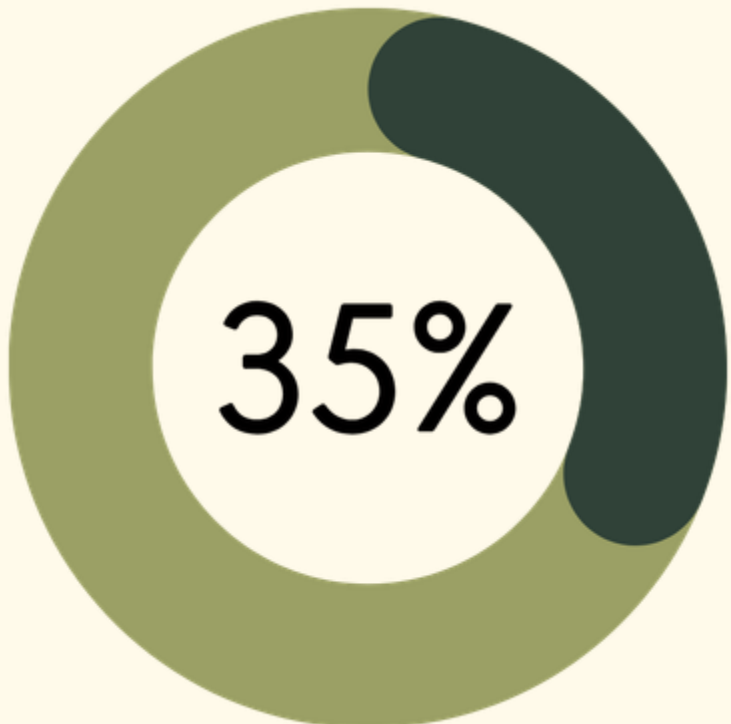
Madeline Delage, MA
University of Rochester



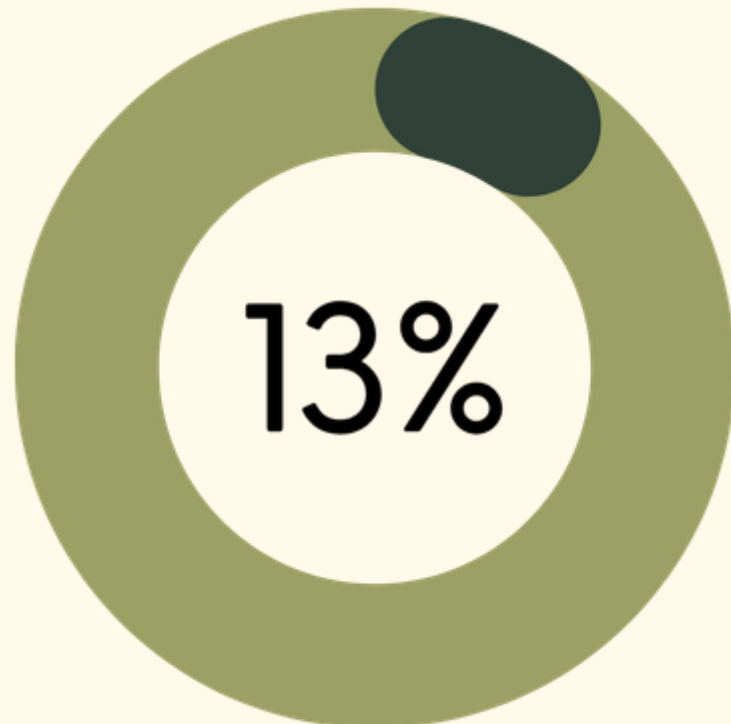
Mental Health in FASD



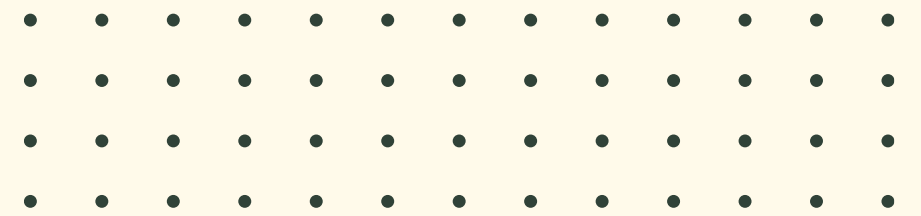
mental health challenges



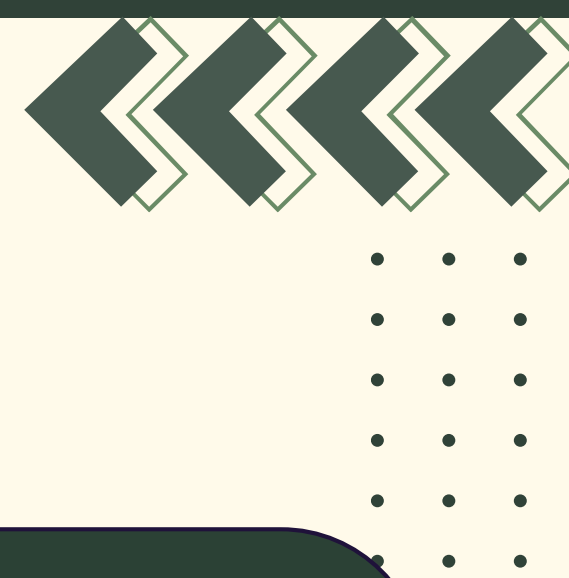
suicide ideation



suicide attempt

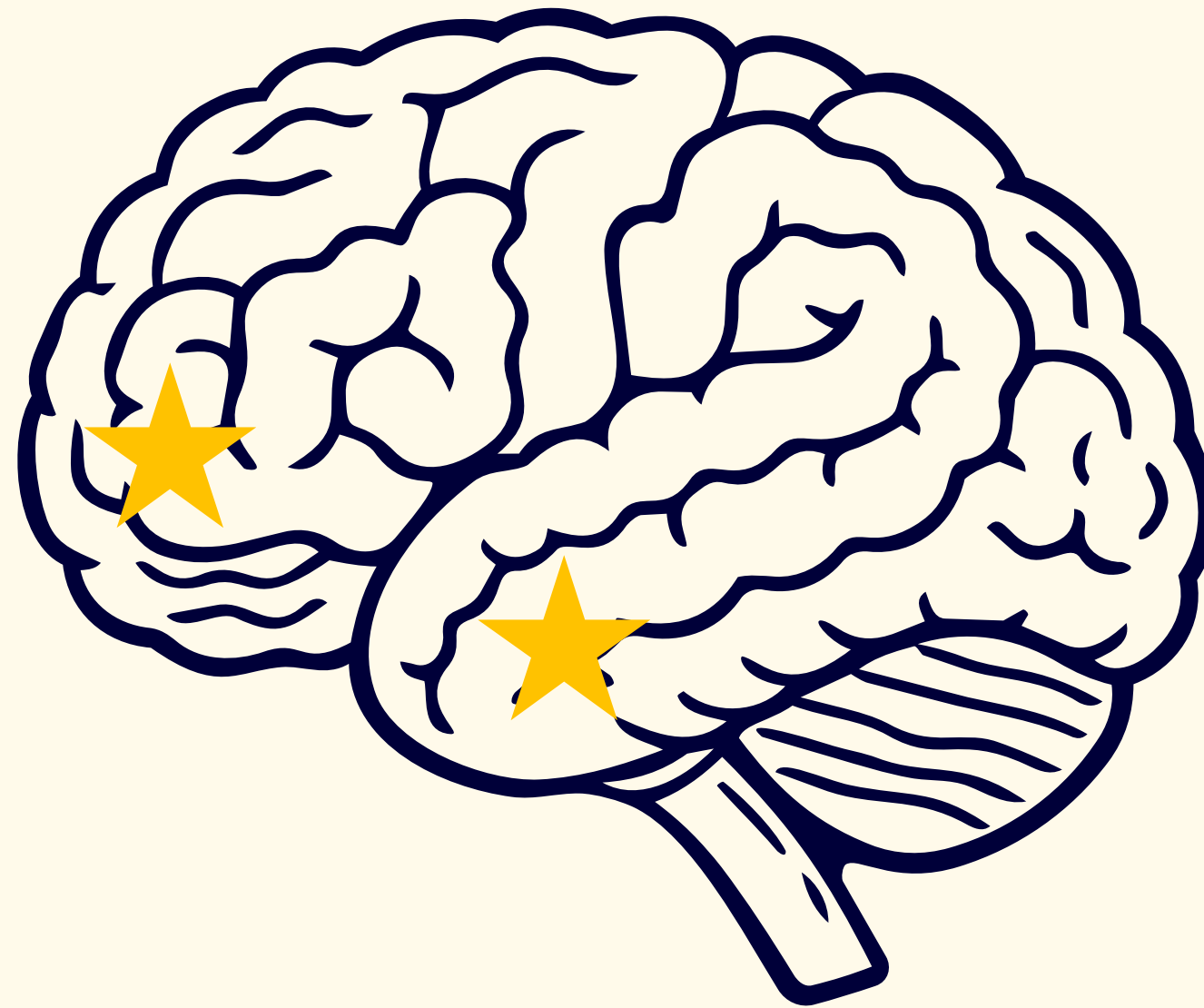


Mental Health in FASD



Prefrontal cortex =
"control center"

Adolescence is a high-
risk period for mental
health challenges



Higher rates of adversity
and traumatic
experiences

Amygdala =
"alarm system"





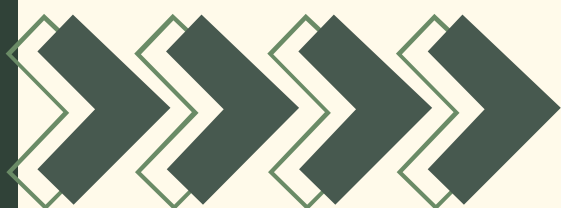
The Core Problems

1

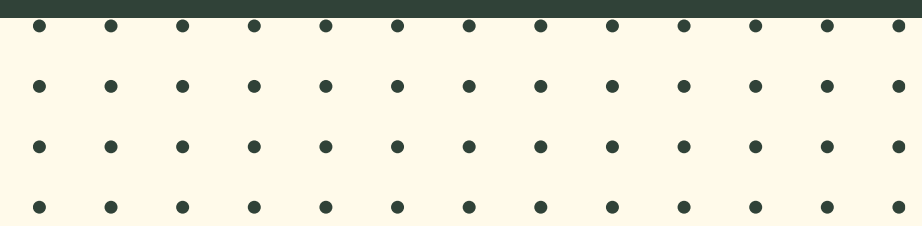
There are no evidence-based mental health interventions adapted or made for teens with FASD.

2

We are asking teens with FASD to succeed in treatments that were not designed for them.



Possible Solution?



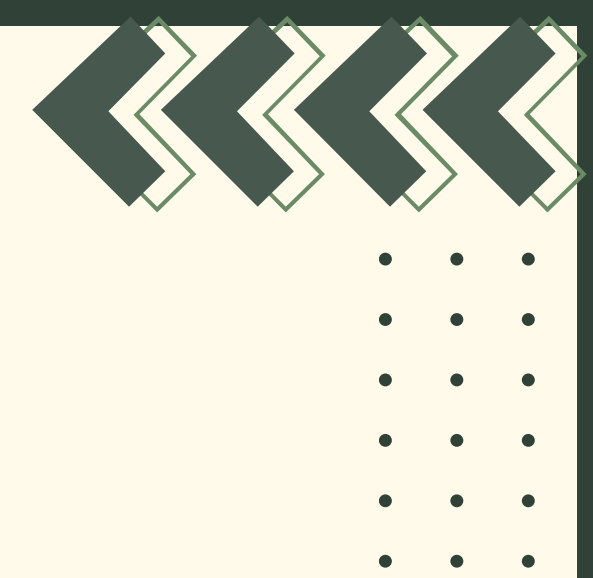
**A guide for adapting mental health
interventions**

FASD-informed

Evidence-based

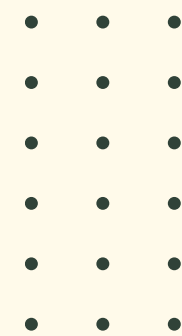
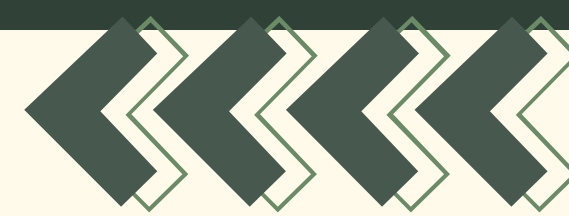
Accessible

The Promise of Dialectical Behavior Therapy (DBT)



- The FASD community has identified mental health as a main challenge
- “Gold standard” in treatment
- Highlighted as an area of study for teens with FASD

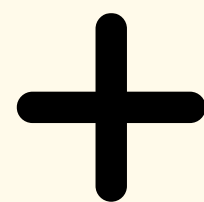
Biosocial Model of DBT



**biological
vulnerability**

**invalidating
environment**

**brain-based differences
associated with
teratogenic
impact of PAE**

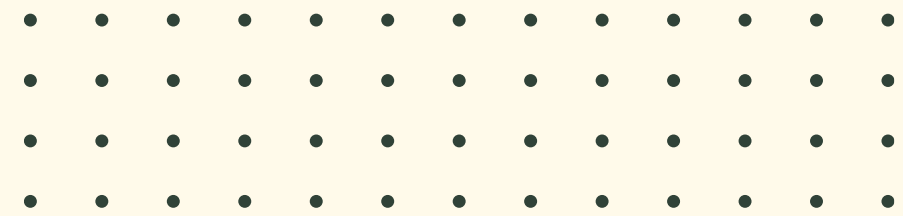


**disability stigma
lack of support/services
lack of knowledge on FASD
multiple home transitions
misinterpretation of
behavior
trauma**

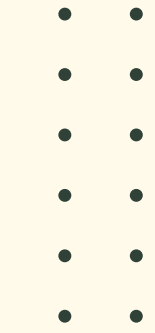


**severe
emotion
dysregulation**

**plus all the other
invalidating environments
teens encounter!**



DBT Structure

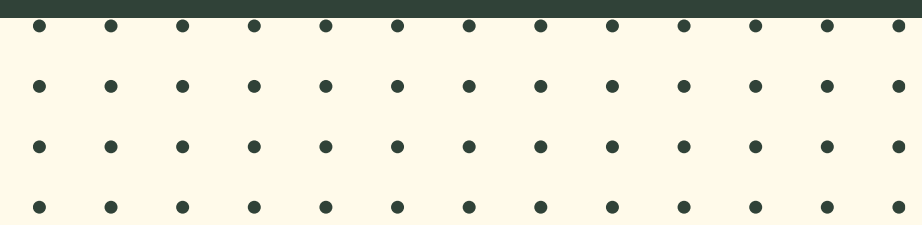


Goal: Build a Life Worth Living

mindfulness - distress tolerance - interpersonal effectiveness -
walking the middle path - emotion regulation

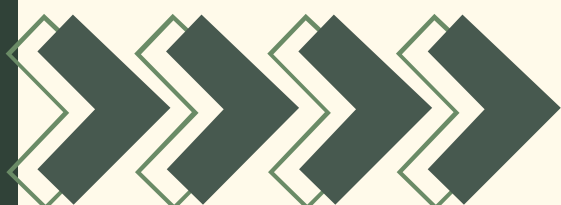
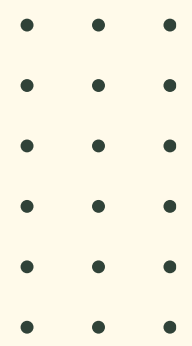
Linehan et al., 1991, 1999; Miller et al. 2006

DBT & Neurodivergence

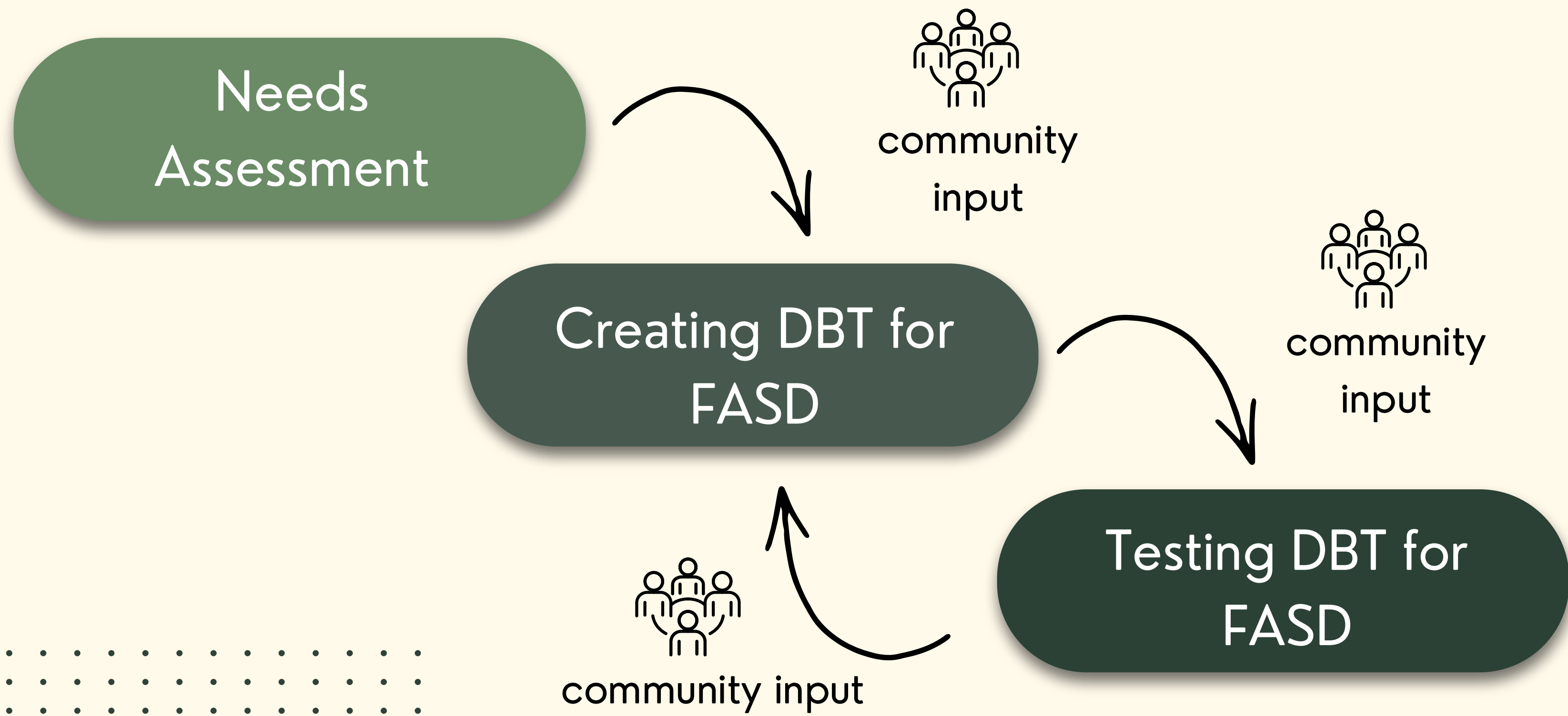
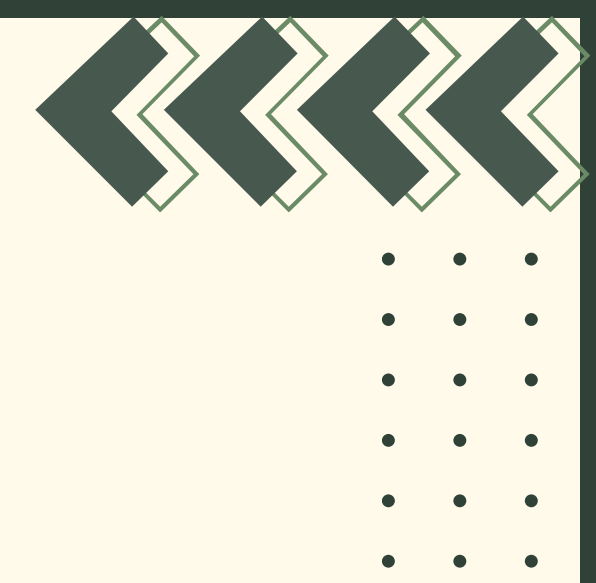


Autism - ADHD - Intellectual Disability - Learning Disability

- Shows promise in other neurodiverse populations
- What adaptations were used?
 - Simplified language
 - Slower pacing
 - Increased repetition
 - Visual and concrete supports
 - Caregiver support



Development and Testing of DBT for FASD



Methods

Teens (n=12) & Caregivers (n=13)

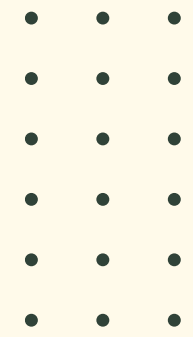
- Watched short videos explaining DBT skills.
Answered questions about:
 - How helpful each skill seemed
 - How hard or easy it might be to use
- Caregivers also shared:
 - What might make it easier or harder to participate

DBT Clinicians (n=24)

- Assessed:
 - Prior training in FASD
 - Experience with neurodivergent clients
 - Training needs and interests
- Identified:
 - Needed adaptations to DBT-A
 - Barriers and facilitators to implementation

- Teens and caregivers gave insight in to:
 - The fit of DBT
 - Which skills were most challenging and most helpful
 - Concrete suggestions on skill modification
- Clinicians gave insight in to:
 - Training needs on FASD
 - Clinic structure barriers and facilitators
 - Past DBT work with neurodivergent populations

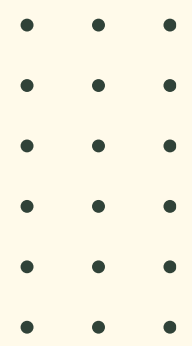
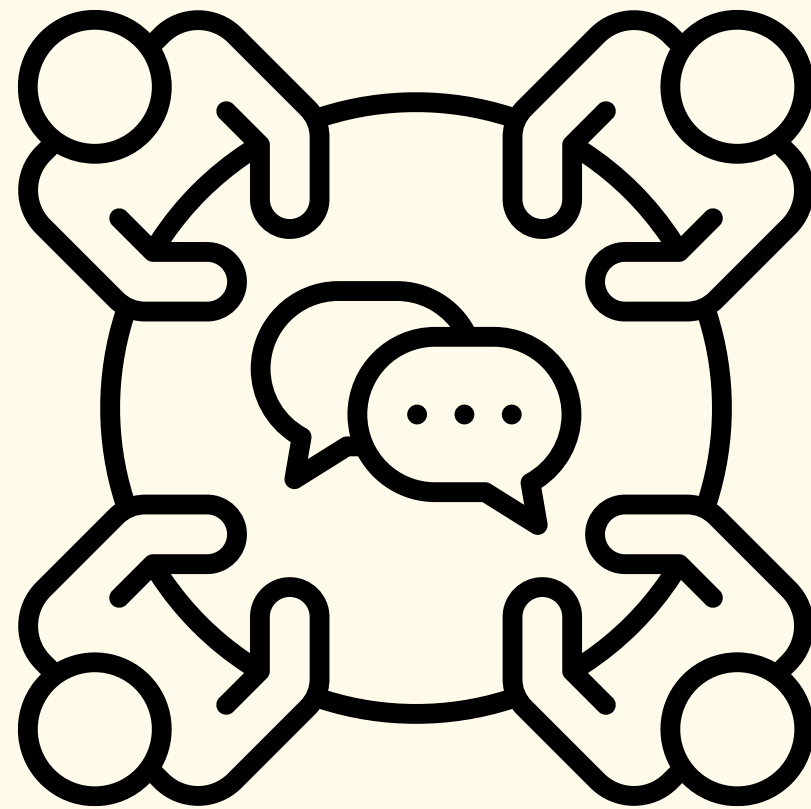
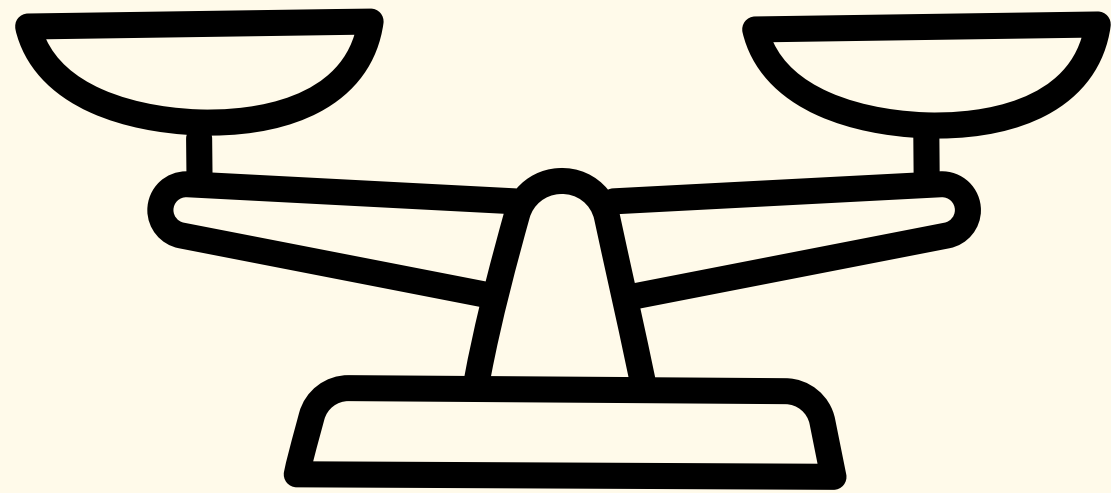




Creating DBT for FASD

fidelity

accessibility

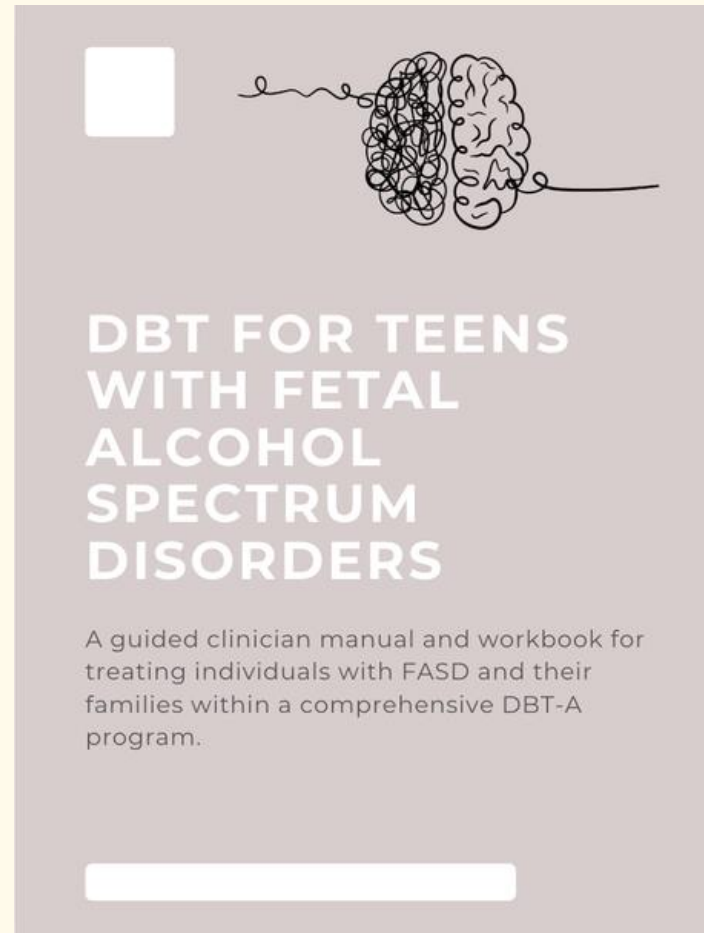




Creating DBT for FASD

For clinicians working with teens with FASD

Manual

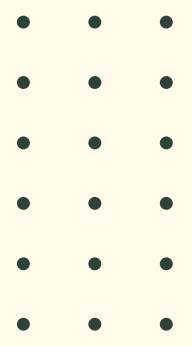


- Why?**
- DBT was not made for people who learn differently
 - All aspects of the program were modified
 - Concepts can be confusing without concrete explanations and examples

Trainings



- Why?**
- Clinicians have little to no training on FASD
 - It's hard to teach DBT for FASD if you don't understand how FASD affects learning
 - Clinicians need support to adapt in the moment





Creating DBT for FASD

For teens with FASD and caregivers


Introductory Materials

FOUR PARTS OF DBT-A







Individual Therapy
Individual therapy involves one-on-one sessions with a therapist, where teens discuss their challenges and work on using the skills they've learned.




Skills Group
In skills group, teens and their caregivers learn and practice important skills to help them manage their feelings and problems better.



Phone Coaching
Phone coaching allows teens to call their therapist for help when they need support using their skills in tough situations.




Consultation Team
The consultation team is a group of therapists who work together to share ideas and support each other in helping their teen clients.




Adapted Group Skills Slides


Welcome back to DBT group!



Distress Tolerance
We are going to create a toolkit of skills for you to have when you are in crisis



Workbook



DBT FOR TEENS WITH FETAL ALCOHOL SPECTRUM DISORDERS

A workbook for teens with FASD and their caregivers.

Diary Cards

days of the Week	Did you think about hurting yourself?	How many hours did you sleep?	Did you take your meds?	*You pick!*	Which emotions were the most intense today?	What DBT skill did you use?
MONDAY	Yes No		Yes No		😞 😡 😭 😍 😊	
TUESDAY	Yes No		Yes No		😞 😡 😭 😍 😊	
WEDNESDAY	Yes No		Yes No		😞 😡 😭 😍 😊	
THURSDAY	Yes No		Yes No		😞 😡 😭 😍 😊	
FRIDAY	Yes No		Yes No		😞 😡 😭 😍 😊	
SATURDAY	Yes No		Yes No		😞 😡 😭 😍 😊	
SUNDAY	Yes No		Yes No		😞 😡 😭 😍 😊	

Today's Date:

Did you have thoughts of hurting yourself? YES NO

Did you act on those thoughts? YES NO

How many hours of sleep did you get? _____

Did you take your medication? YES NO

INSERT BEHAVIOR YOU WANT TO WORK ON

What emotions were the most intense for you today?
😞
😡
😭
😍
😊
 Other: _____

What DBT skills did you use today? _____

Creating DBT for FASD

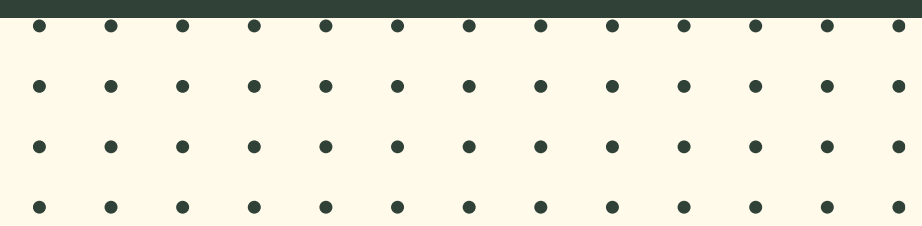
Major Adaptation Themes

The Why

- Big or abstract words can be challenging
- Attention span can be shorter
- Memory challenges
- Processing speed challenges
- Abstract ideas can be confusing
- Predictability can help with learning
- Too much at once can be overwhelming

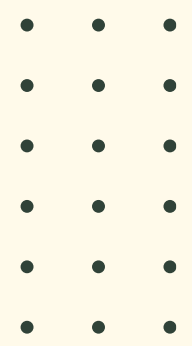
The What

- Simpler language and visuals
- More breaks
- More repetition
- Slower pacing
- Concrete examples
- Consistent structure
- Smaller chunks of information



Methods

- Single-arm mixed-methods feasibility trial
- **Participants:** 8 teens with FASD+caregivers, 5 DBT-clinicians
- **Setting:** Outpatient comprehensive DBT clinic
- **Intervention: 30 weeks of adapted DBT for FASD**
- **Research visits**
 - Emotion regulation, internalizing and externalizing behaviors
 - Exit interviews

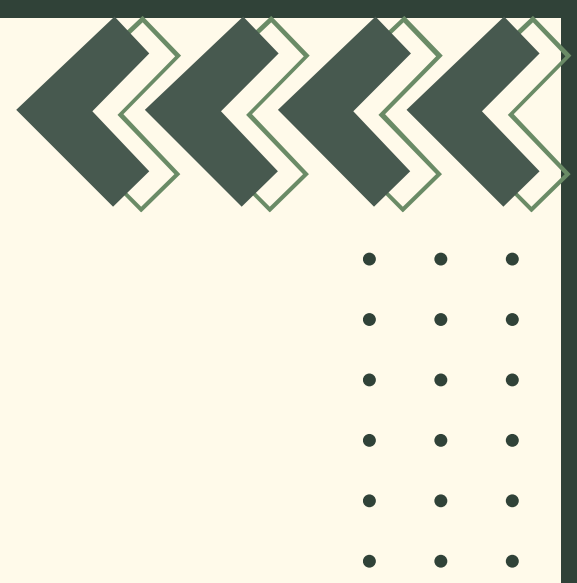


Testing DBT for FASD

Aims

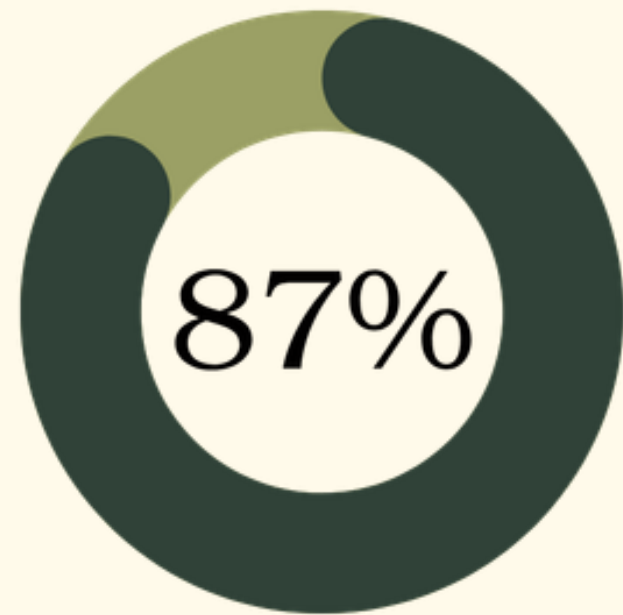
- Feasibility - Can we do this?
- Fidelity - Can we stick to DBT?
- Acceptability - Do people like it?
- Preliminary clinical efficacy - Did it work?

Testing DBT for FASD

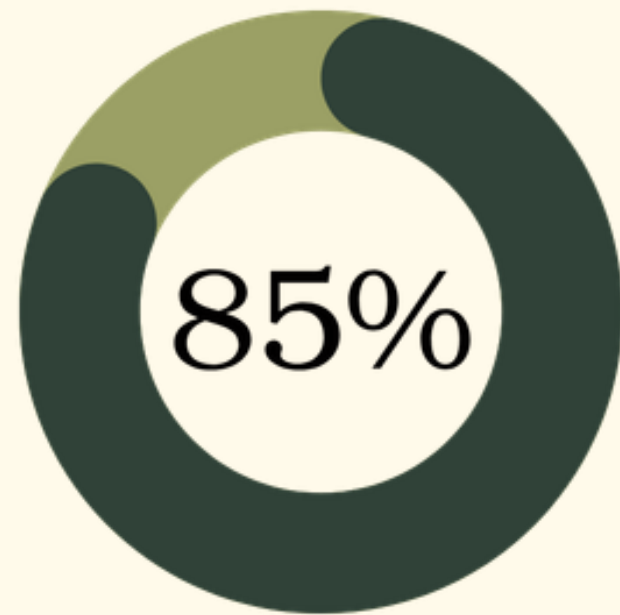


Results

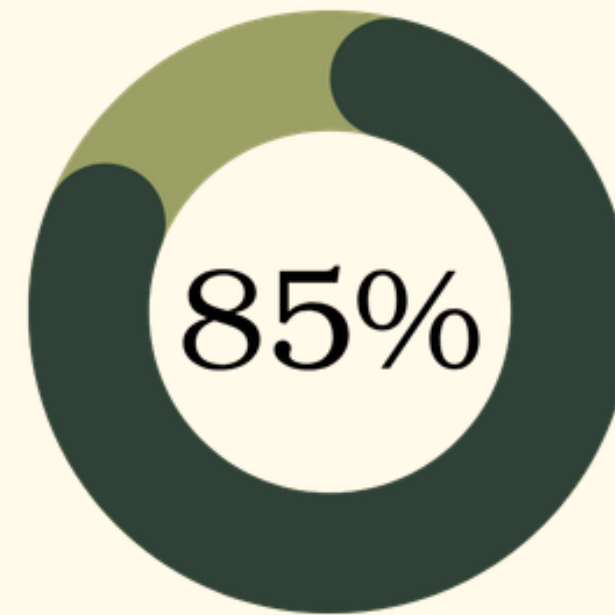
Can we do this? Can we stick to DBT? Yes!



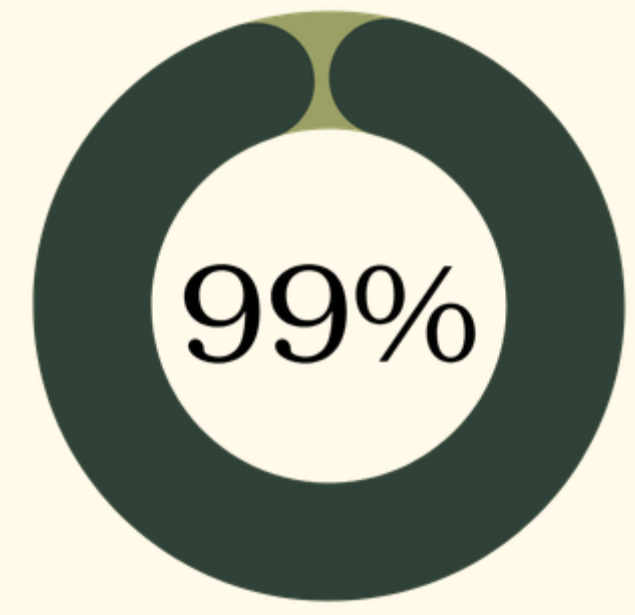
Completion



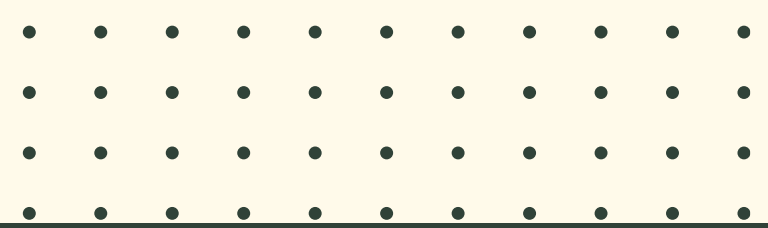
Attendance

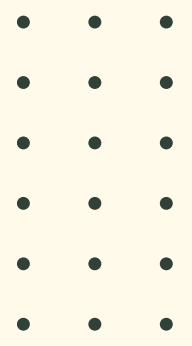


Engagement



Fidelity



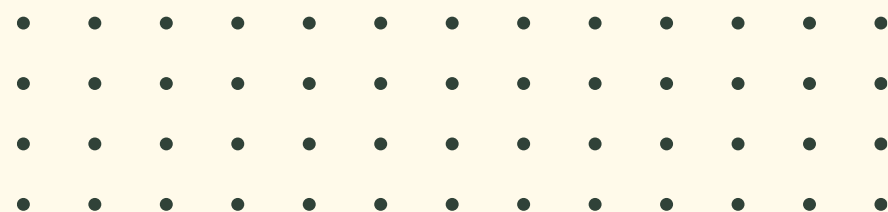


Results

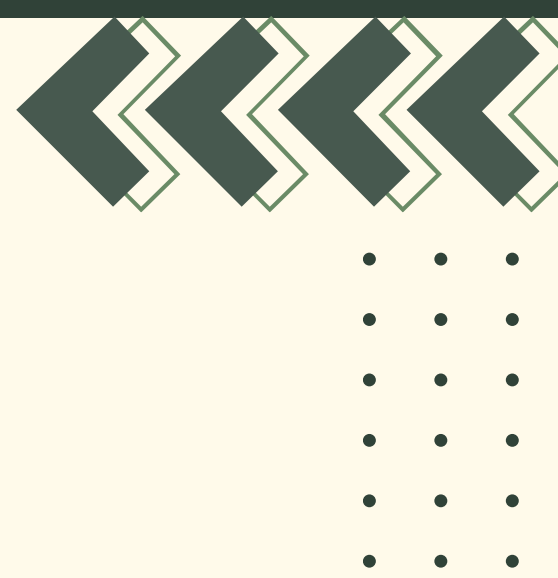
Can we do this? Can we stick to DBT? Yes!

“It flowed right into the structure of how we do things. We’ve got comprehensive DBT so it's set up to work for a clinic that already does that.”

“We followed the rules of DBT... it didn’t feel like any of the rules were different.”

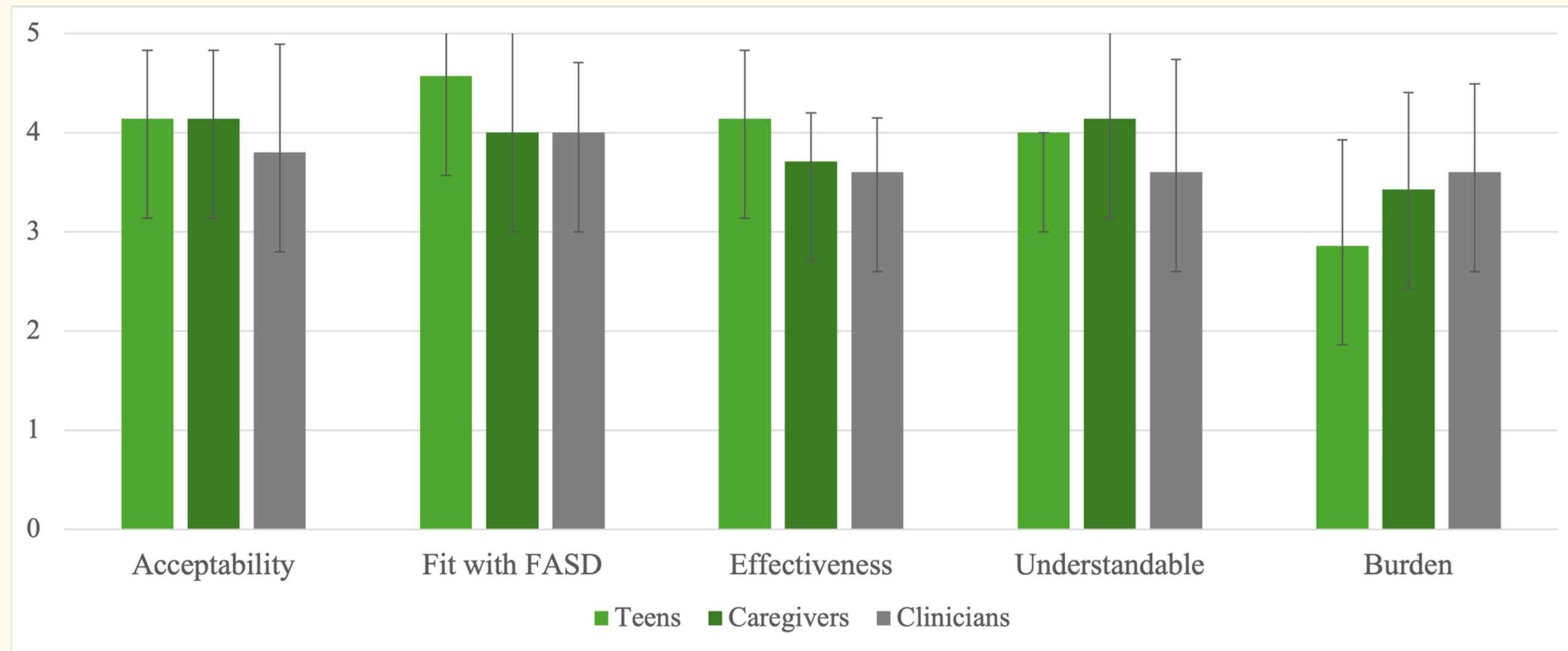


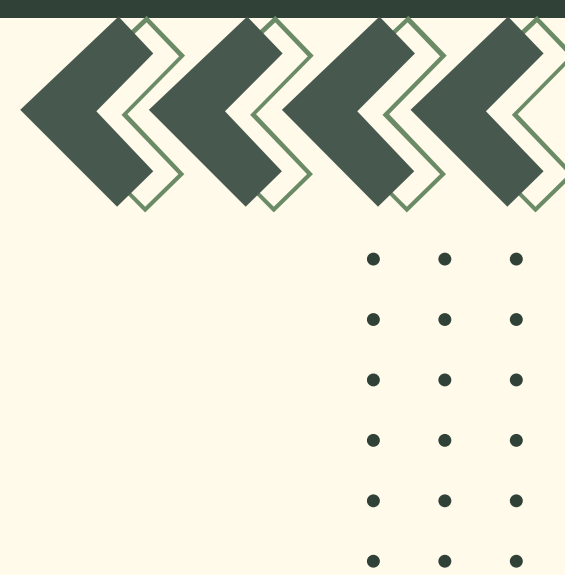
Testing DBT for FASD



Results

Did People Like It?
Yes! And...





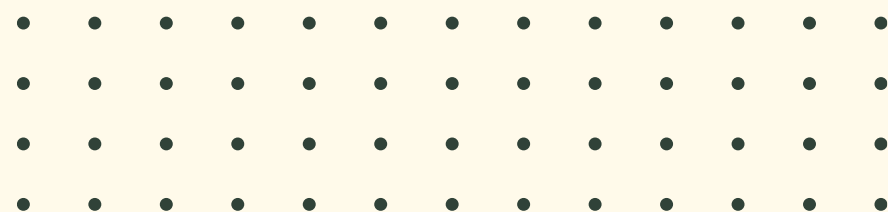
Results



Did People Like It?
Yes! And...

“I liked it because... it was geared to FASD... other therapies have been more generic, and haven’t really focused on [symptoms of FASD]”

‘Yeah. I liked it. It was more like [therapist] heard me a lot. She was very easy to talk to, good listener... I think she did understand my needs.’



Testing DBT for FASD

Results

Did People Like It?
....No

Teen

- Shorter sessions
- More hands-on activities
- Clearer, easier-to-use tools

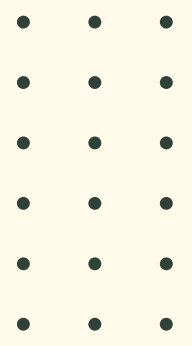
Caregiver

- Practice with skill-outside of therapy
- Additional concrete examples
- Caregiver-specific support group

Clinician

- More training on FASD-specific behaviors
- Ongoing consultation support

Areas for Change



Results

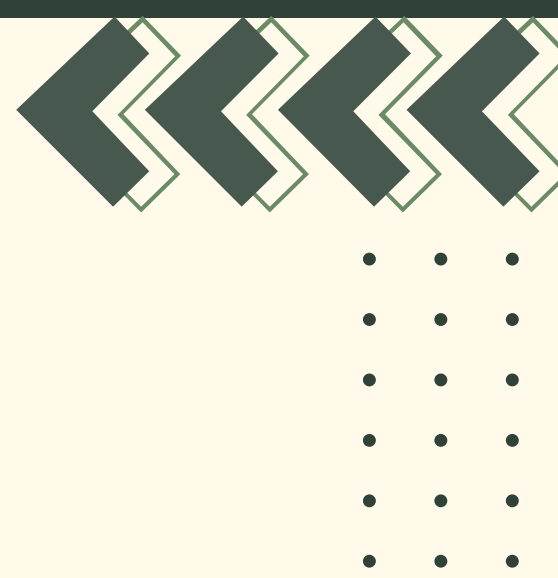
Did it help? (preliminary)
Yes(?)

- Every teen showed reliable change in at least one domain
- Improvements in:
 - Anxiety
 - Depression
 - Overall behavior challenges
 - Attention
 - Social functioning

Questionnaires:

Difficulties in Emotion Regulation Scale (Bjureberg et al., 2017)

Child Behavior Checklist(Achenbach, 2000)



Results



Did it help? (preliminary)
Yes(?)

“My daughter made more progress in six months than she did in three years with her other therapy”

“It helped me. It mostly just gave me an idea of how to be more calm.”

“I really think it helped me have another perspective on my mom. I think it was very helpful for us to get a better relationship and just be able to be like a better person overall. I feel like that really helped.”

A Model for Mental Health Adaptation for FASD

Research Driven Model



Co-Define the Problem

Multi-Informant Needs Assessment

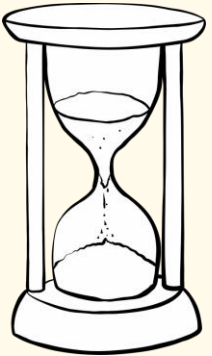
Ground adaptation in living experience and theory

Systematic adaptation design

Workforce preparation and collaborative training

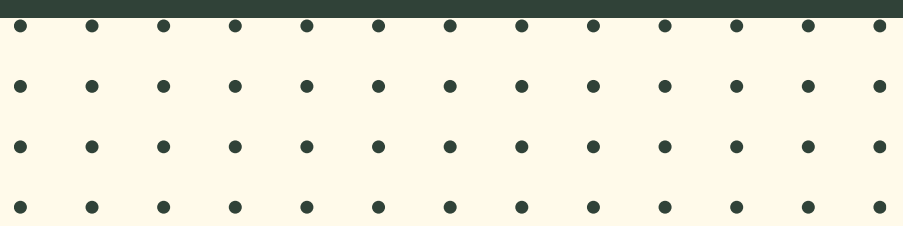
Feasibility trial with feedback from community

Continuous refinement and plan for larger testing



Manual coming soon...

A Model for Mental Health Adaptation for FASD



Research Driven Model

- Co-Define the Problem
- Multi-Informant Needs Assessment
- Ground adaptation in living experience and theory
- Systematic adaptation design
- Workforce preparation and collaborative training
- Feasibility trial with feedback from community
- Continuous refinement and plan for larger testing



Clinician Driven Model

- Begin with relationship building
- Identify barriers in existing interventions
- Preserve core treatment elements
- Modify delivery for neurodevelopmental fit
- Adjust expectations for progress
- Build FASD community connection
- Engage in ongoing consultation



*Research Driven Model,
Clinician Driven Model,
Information on DBT Skills for Teens*

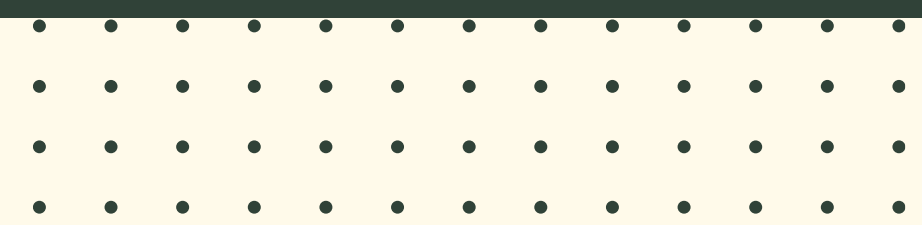
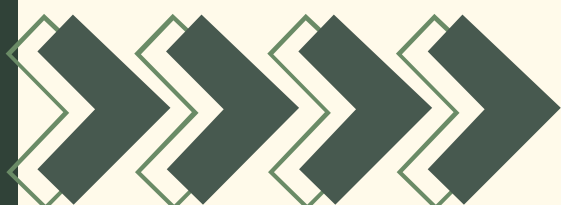
Conclusion

Mental health needs in FASD are real and urgent

Fit matters as much as the treatment itself

Adapted DBT-A is feasible, accessible, and promising

The process matters: build with the FASD community





Thank You

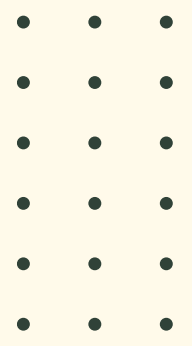


GENESEE VALLEY PSYCHOLOGY



Especially to the teens with FASD and families who made this work possible.

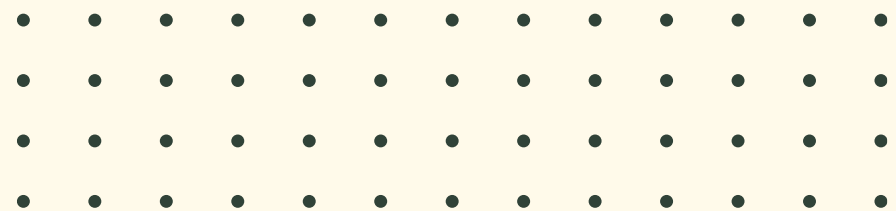
mrockhol@ur.rochester.edu



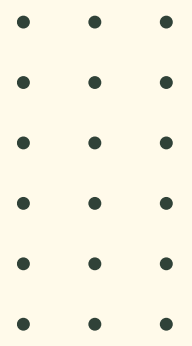
Results

Did people interact with it?
Yes!

- ~77% session attendance (teens & caregivers)
- ~85% attendance among completers
- High in-session engagement:
 - Listening: ~96–99%
 - Participation: ~85%
- Moderate homework and diary card completion (~45–65%)

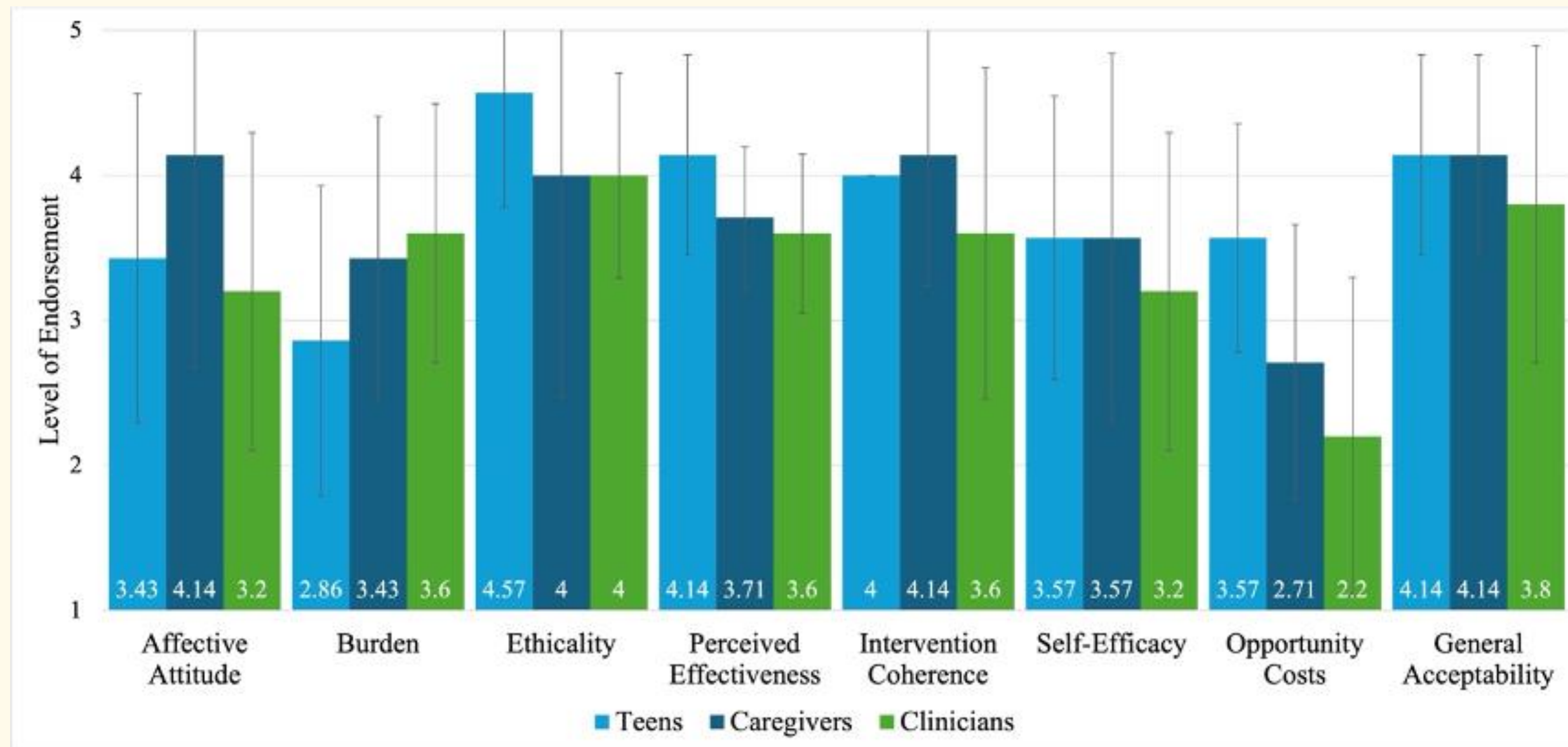


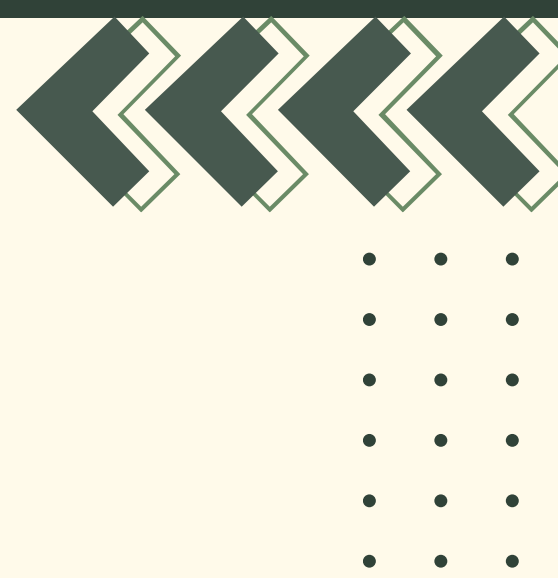
Testing DBT for FASD



Results

Did People Like It?
Yes! And...



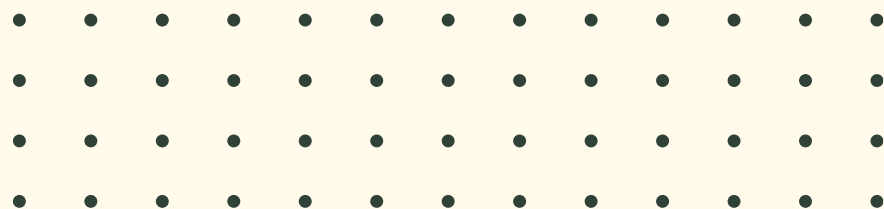


Results

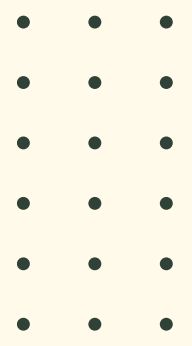
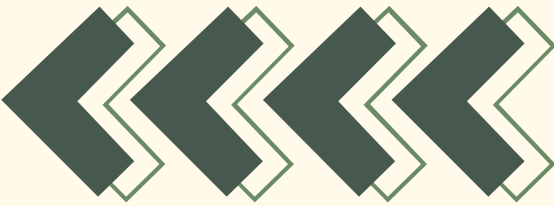
Did we stick to the EBI?
Yes(?)

- Fidelity assessed using DBT Adherence Checklist (DBT AC-I)
- 15% of sessions randomly selected and coded
- Mean fidelity score: **23.88 (out of 26)**
- Benchmark for fidelity: 24
- Majority of sessions met or closely approached benchmark

“We followed the rules of DBT... it didn’t feel like any of the rules were different.”



Testing DBT for FASD



$$RCI = \frac{X_2 - X_1}{SD \cdot \sqrt{2(1 - r)}}$$

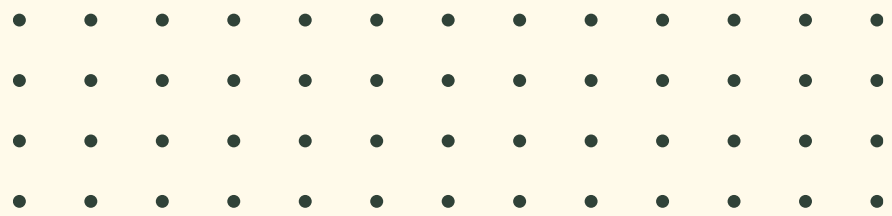


Table 15. Reliable Clinical Change in DBT-A for FASD

Measure	Percentage Showing Reliable Change (n=7)
Teen Report	
YSR CBCL Total Score	42.86% (n=3)
YSR CBCL Anxious/Depressed	14.29% (n=1)
YSR CBCL Withdrawn/Depressed	14.29% (n=1)
YSR CBCL Somatic Problems	28.57% (n=2)
YSR CBCL Social Problems	28.57% (n=2)
YSR CBCL Thought Problems	42.86% (n=3)
YSR CBCL Attention Problems	28.57% (n=2)
YSR CBCL Rule Breaking	0.00% (n=0)
YSR CBCL Aggression Problems	14.29% (n=1)
YSR CBCL Internalizing Total	14.29% (n=1)
YSR CBCL Externalizing Total	14.29% (n=1)
DERS Total	0.00% (n=0)
DERS Awareness	14.29% (n=1)
DERS Clarity	0.00% (n=0)
DERS Goals	14.29% (n=1)
DERS Impulse	0.00% (n=0)
DERS Non-Acceptance	0.00% (n=0)
DERS Strategies	0.00% (n=0)
Caregiver Report	
CBCL Total Score	42.86% (n=3)
CBCL Anxious/Depressed	14.29% (n=1)
CBCL Withdrawn/Depressed	0.00% (n=0)
CBCL Somatic Problems	14.29% (n=1)
CBCL Social Problems	0.00% (n=0)
CBCL Thought Problems	14.29% (n=1)
CBCL Attention Problems	28.57% (n=2)
CBCL Rule Breaking	0.00% (n=0)
CBCL Aggression Problems	0.00% (n=0)
CBCL Internalizing Total	42.86% (n=3)
CBCL Externalizing Total	0.00% (n=0)
DERS Total	0.00% (n=0)
DERS Awareness	14.29% (n=1)
DERS Clarity	14.29% (n=1)
DERS Goals	0.00% (n=0)
DERS Impulse	28.57% (n=2)
DERS Non-Acceptance	28.57% (n=2)
DERS Strategies	0.00% (n=0)

Note. YSR=youth self report; CBCL= Child Behavior Checklist, DERS=Dimensions of Emotion Regulation Scale