

Fetal Alcohol Spectrum Disorders: Lived Experiences, Strengths, & Interventions



UNIVERSITY *of*
ROCHESTER

Mt.
HOPE
family center

CHRISTIE L. M. PETRENKO, PH.D.

FASD United / USUHS
September 2022

**WHAT ARE THE LIVED
EXPERIENCES OF PEOPLE
WITH FASD & THEIR
FAMILIES?**

STIGMA

Public stigma is pervasive and severe

Internalized self-stigma, shame, guilt

Contributes to under-diagnosis and low access to services

- Mothers uncomfortable talking about PAE or seeking supports
- Providers not asking about PAE; afraid to label a child with FASD

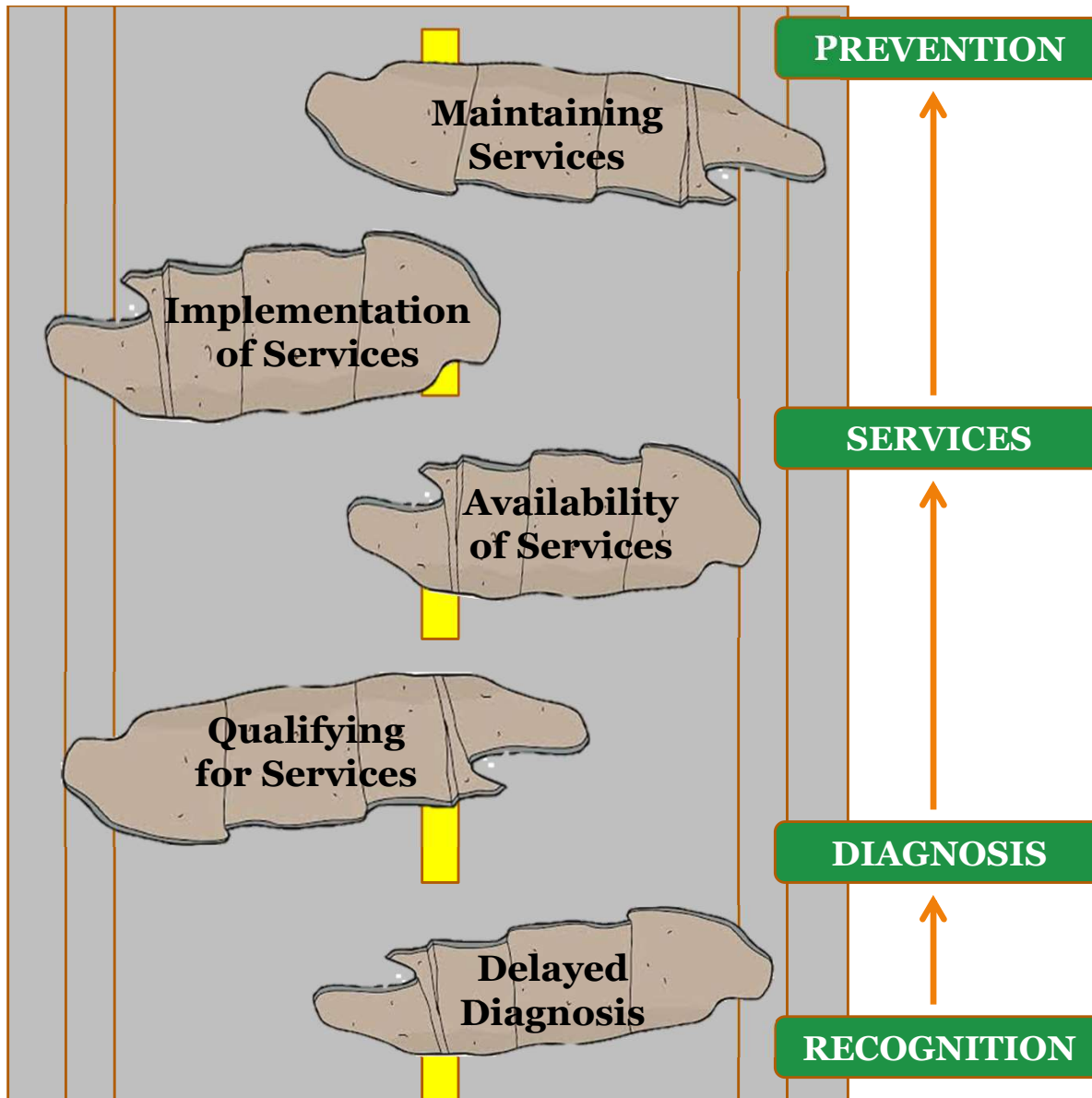
People with FASD feeling “less than”



<https://www.nofas.org/stigma/>

For review: Roozen et al., 2020

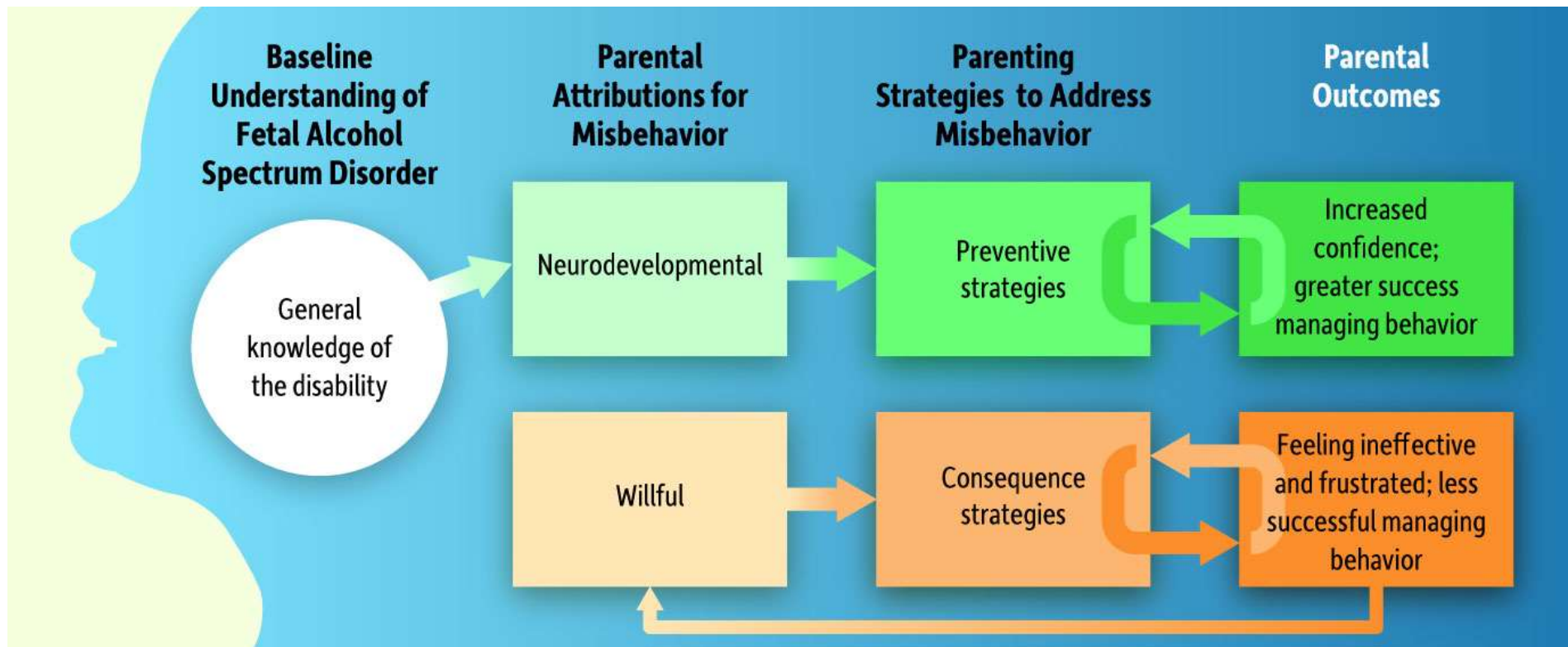
Lack of Knowledge of FASD



**What are the
Barriers to
Supporting
People with
FASD?**

Petrenko et al., 2014

FASD SYMPTOMS ARE EASILY MISUNDERSTOOD



Petrenko et al., 2016

FEELING DIFFERENT

Awareness of difficulties → limiting

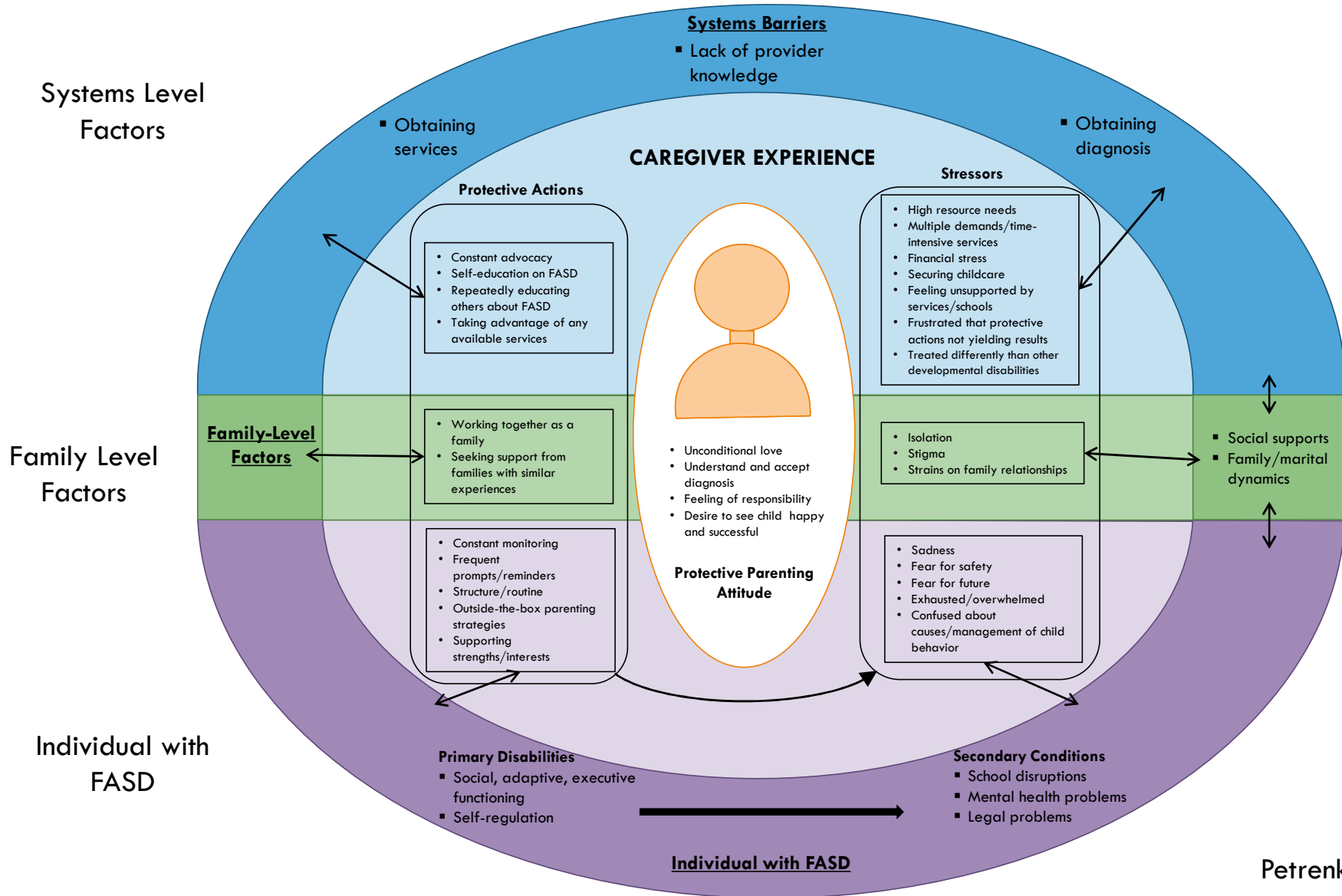
Under-supported, discrimination

FASD feels unfair

Difficulty coping

Persistence





PEOPLE WITH FASD HAVE IMPORTANT STRENGTHS

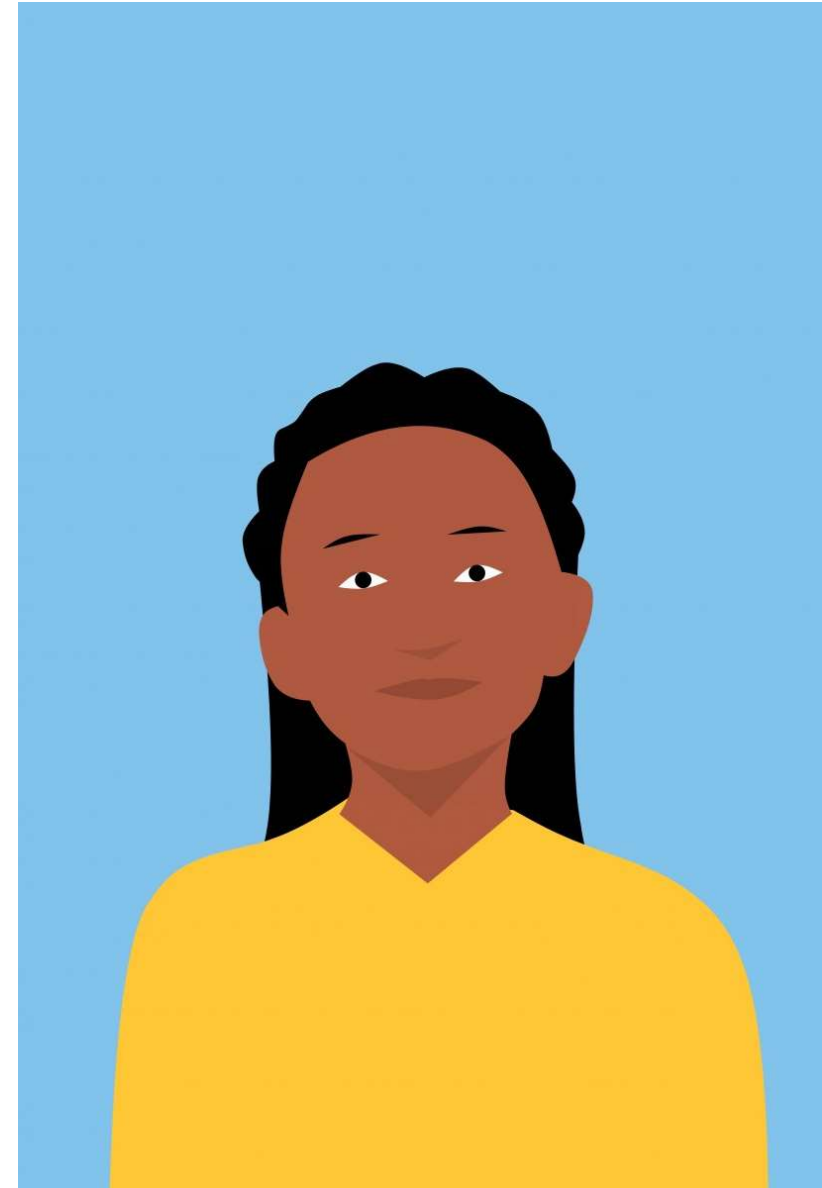


PEOPLE WITH FASD ARE CAPABLE

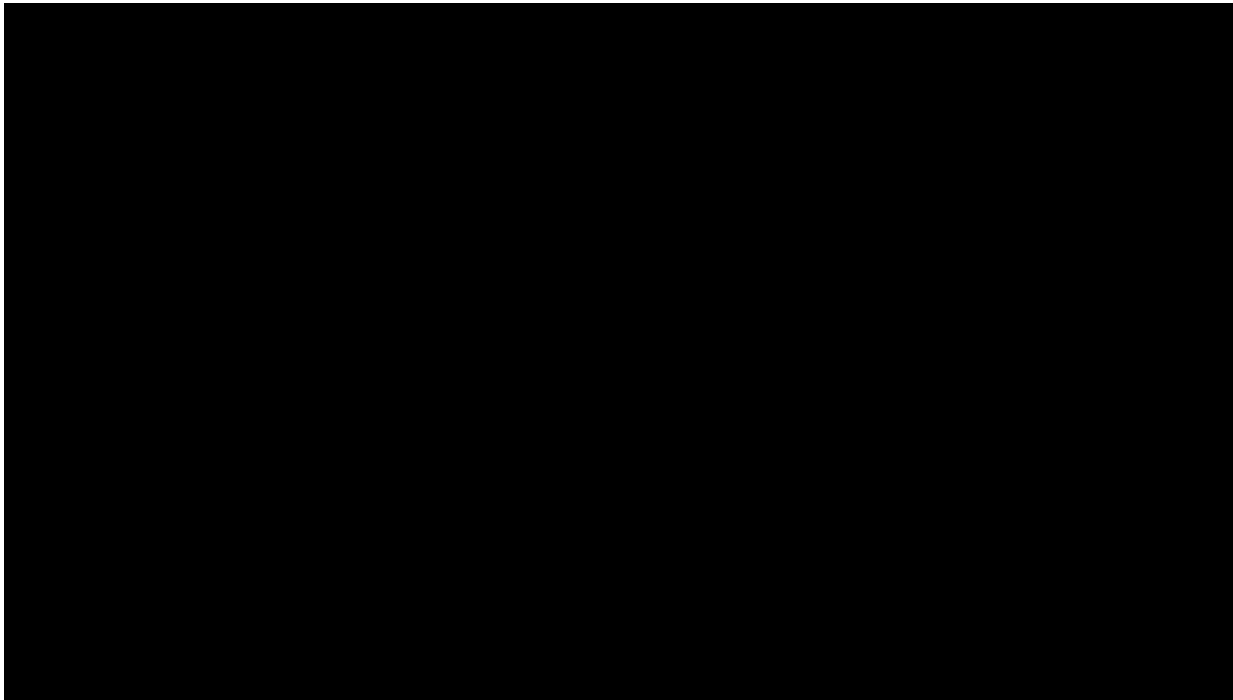
The key is to provide opportunities
and supports...

for people to use their strengths and
abilities...

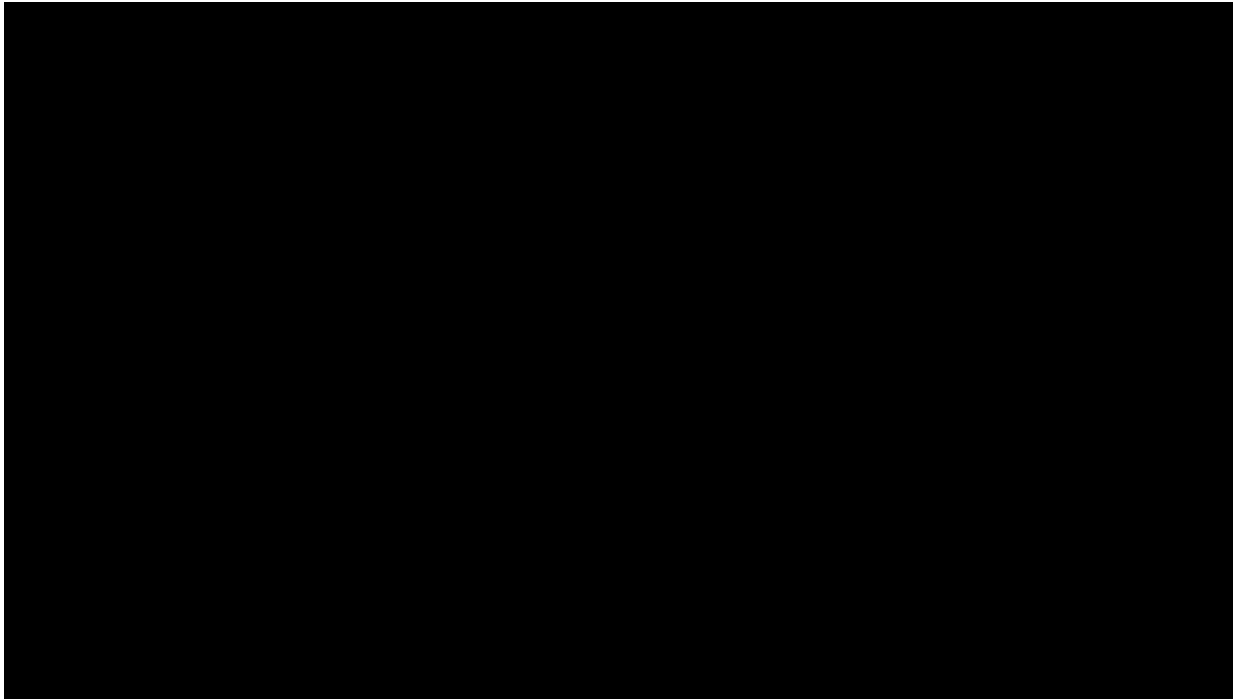
in meaningful activities and
relationships.



SAM'S PERSPECTIVE



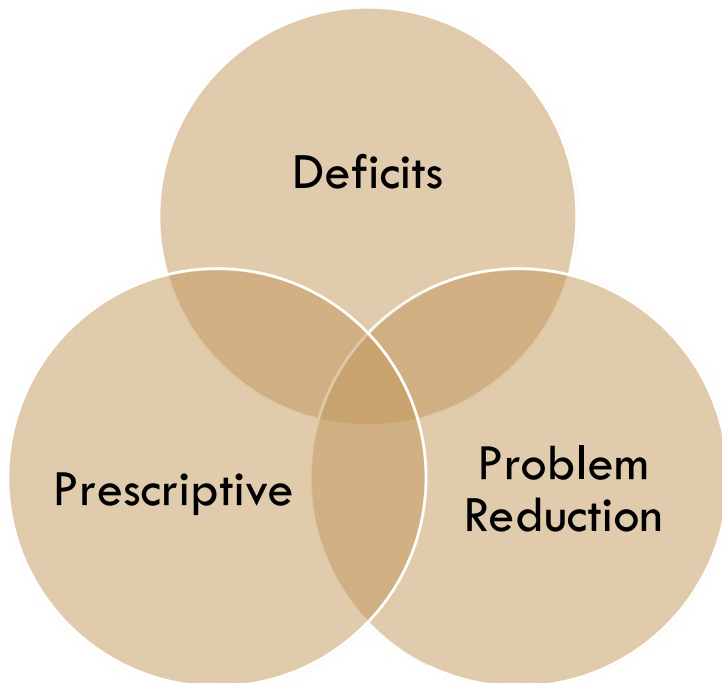
JACQ'S PERSPECTIVE (SAM'S SISTER)



Surviving

Feeling different, unsupported,
stigmatized.

Deficit-Focused Intervention



Addressing Barriers

Awareness &
Understanding

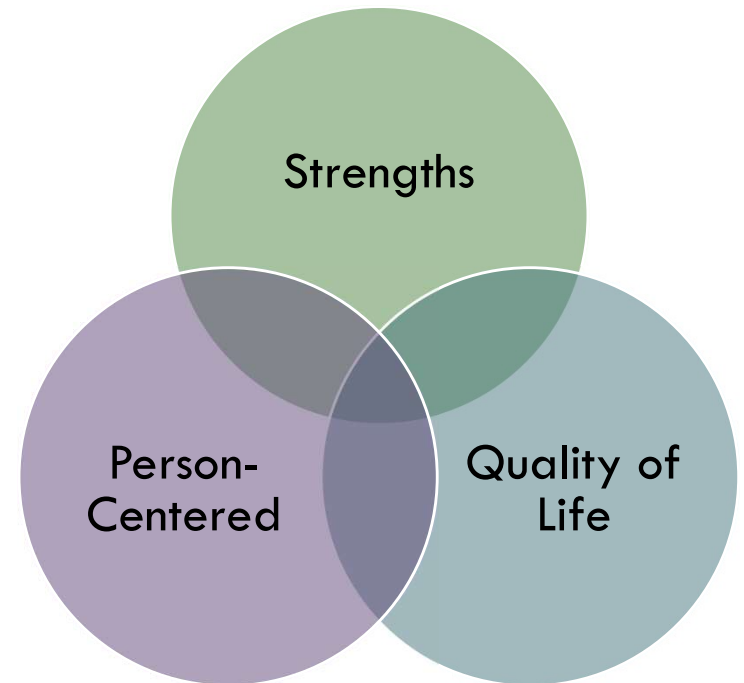
Access to Care

Reduce Stigma

Thriving

Feeling valued, supported,
included.

Strengths-Based Intervention





FASD INTERVENTION RESEARCH

How are we doing?

SURVEY OF EXISTING INTERVENTIONS

People with FASD and their families benefit from interventions

Most studied for 3 to 12 age range

Target skill-building and/or environmental supports

Some recognize strengths in conceptual model or intervention design

Outcome measurement largely deficit or problem reduction



Self-regulation and attention



Social skills



Academic skills



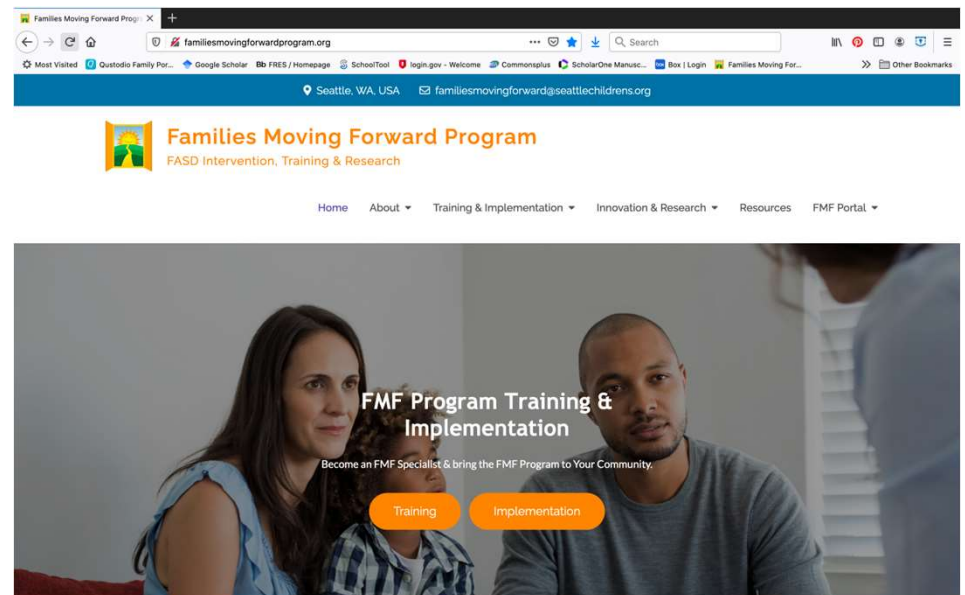
Parent training

EXAMPLE: FAMILIES MOVING FORWARD (FMF) PROGRAM

- Caregiver-focused
- Integrates:
 - Psychoeducation and support
 - Motivational interviewing
 - Cognitive behavioral strategies
 - Positive behavioral support
 - Advocacy education
- 15-21 sessions

Positive family outcomes: Improved cognitive appraisal of the child and parenting sense of competence, increased family needs, and improved child adaptive behavior and reduced problem behaviors

<http://familiesmovingforwardprogram.org/>



Study #5 in Bertrand, 2009; Olson & Montague, 2011

EXAMPLE: GOFAR



The screenshot shows the do2Learn website interface. At the top, there are navigation buttons for Disabilities, Academics, Social Skills, Behavior Management, Picture Cards, JobTIPS Student, and Products. The main content area is titled "GoFAR Overview". It includes a description of the program, a list of steps (F, A, R), and three large circular icons representing Focus & Plan, Act, and Reflect. A sidebar on the left contains a menu with categories like Teaching the Concepts, Game Practice, Real World Application, and GoFAR Resources.

do2Learn™ Disabilities Academics Social Skills Behavior Management Picture Cards JobTIPS Student Products

GoFAR Overview

The GoFAR program teaches self-regulation and adapting to situations. These are important skills children need to function in their daily lives. Using GoFAR, your child will learn how to organize and think through problems carefully to lessen impulsive or hurried responses.

Your child will use a metacognitive technique called FAR. "Metacognitive" is a word that psychologists use to describe how to understand what we are thinking about and what we are doing.

FAR has 3 steps:

- F** Focus and Plan, where a child learns to focus attention on the work to be done and to come up with a plan to solve the problem;
- A** Act, where the plan is carried out;
- R** Reflect, where the child looks at how the plan worked and discusses how it was successful. If it was not successful, the discussion is about what could be done better.

How To Use This Program

The GoFAR program is designed to provide your child practice using the ideas with real world actions. It involves three separate sections:

1. Identify the existing behavior problems (Teaching the Concepts).
2. Practice the rules in simple games (Game Practice).
3. Transfer the knowledge in situations in the home (Real World Applications).

Empirically Tested:

- 5 individual sessions:
 - Children learn "FAR" technique with computer game
 - Parent training
- 5 joint parent-child sessions
 - apply to real-word situations

Improved Outcomes:

- Adaptive functioning
- Attention
- Behavior Problems

Now available online:

<https://do2learn.com/BehaviorManagement/GoFAR/Overview>

Coles et al., 2015; 2018; Kable et al., 2016

AREAS FOR GROWTH

Accessibility in
the community

Early childhood,
adolescence,
adulthood

Mental health
interventions

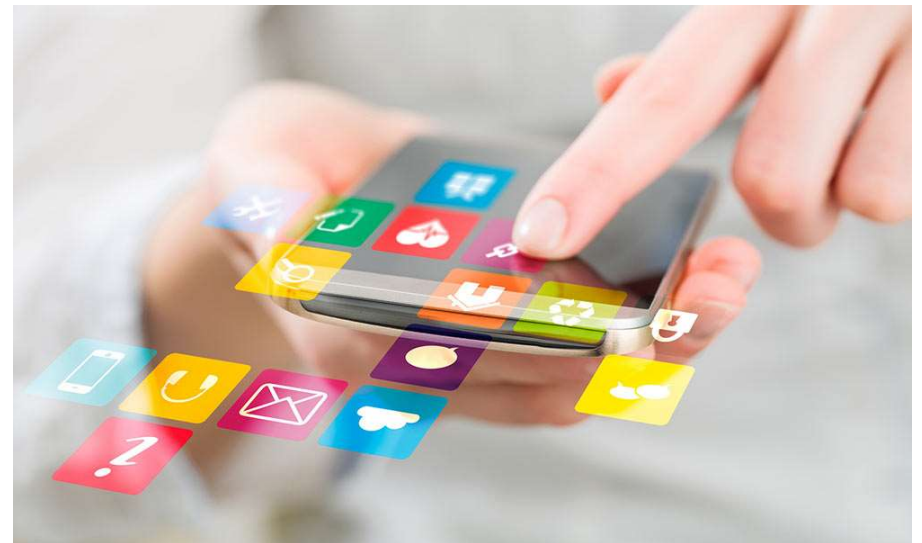
Holistic, person-
centered
frameworks

Outcome
measurement of
strengths and
thriving

Systems and
policy level
interventions

The Possibilities of Mobile Health (mHealth)

- More than 83% of adults own a smartphone worldwide
- Good potential for scalability
- Information can be accessed at any time
- Apps are well suited for:
 - Providing information
 - Self-monitoring tools
 - Goal setting
 - Real-time (synchronous) communication





CIFASD

Collaborative Initiative on
Fetal Alcohol Spectrum Disorders

- HOME
- ABOUT US
- RESEARCH
- PUBLICATIONS
- NEWS
- PARTICIPATE
- EDUCATION
- RESOURCES
- CONTACT
- DATA SHARING



The purpose of this consortium is to inform and develop effective interventions and treatment approaches for Fetal Alcohol Spectrum Disorders (FASD), through multidisciplinary research involving basic, behavioral and clinical investigators and projects. We hope to develop an infrastructure to foster collaboration and coordinate basic, clinical and translational research on FASD.



CIFASD is supported by NIAAA

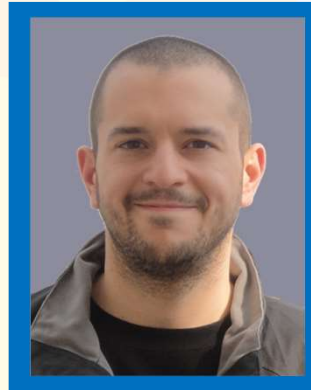
www.cifasd.org 19



Heather Carmichael Olson, Ph.D.
SCRI / U. of Washington



Christie Petrenko, Ph.D.
MHFC / U. of Rochester



Cristiano Tapparelo, Ph.D.
U. of Rochester



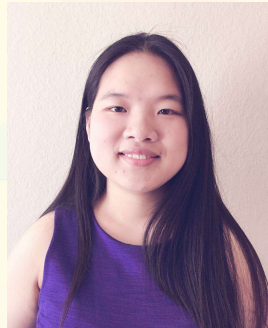
Wendi Heinzelman, Ph.D.
U. of Rochester



Carson Kautz-Turnbull, M.A.
MHFC / U. of Rochester



Alicia Roth
MHFC / U. of Rochester



Shuo Zhang
MHFC / U. of Rochester

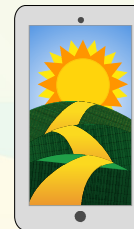


Maddy Rockhold
MHFC / U. of Rochester



Cody Romanos
U. of Rochester

- Families Moving Forward (FMF) Program:
Content, principles, methods
- FMF developed by Heather Carmichael Olson and team at UW/SCRI
- Funded by CDC
- FMF Connect is a derivative product with unique features



Families Moving Forward
CONNECT

Learning Modules

- 12 core modules, 3 levels
- Educational text/audio
- Exercises to practice content
- Animation and video

Notebook

- User builds personalized section for later reference
- Exercises about child, selected content, tools, notes

Dashboard

- Summary of progress
- Badges earned, child behavior ratings, usage metrics

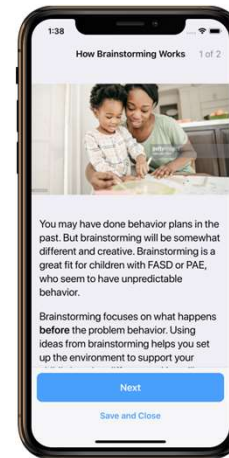
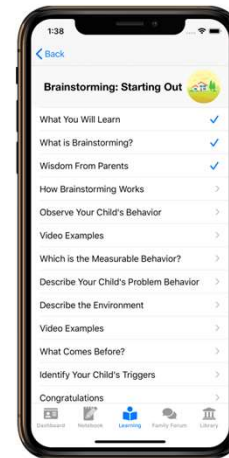
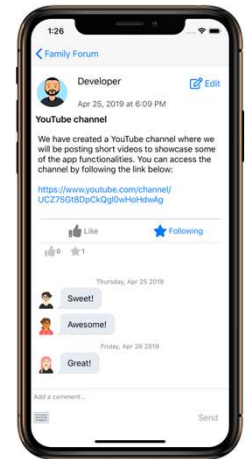
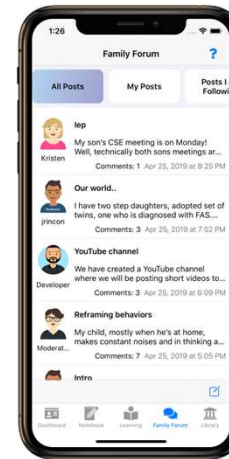
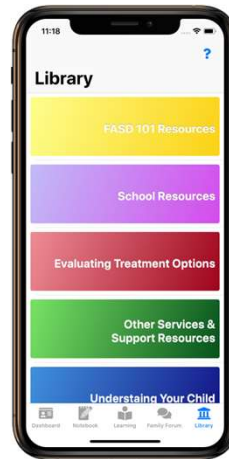
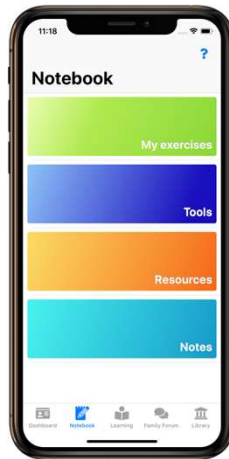
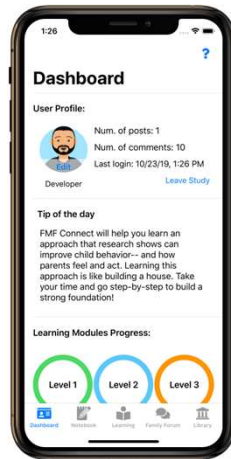


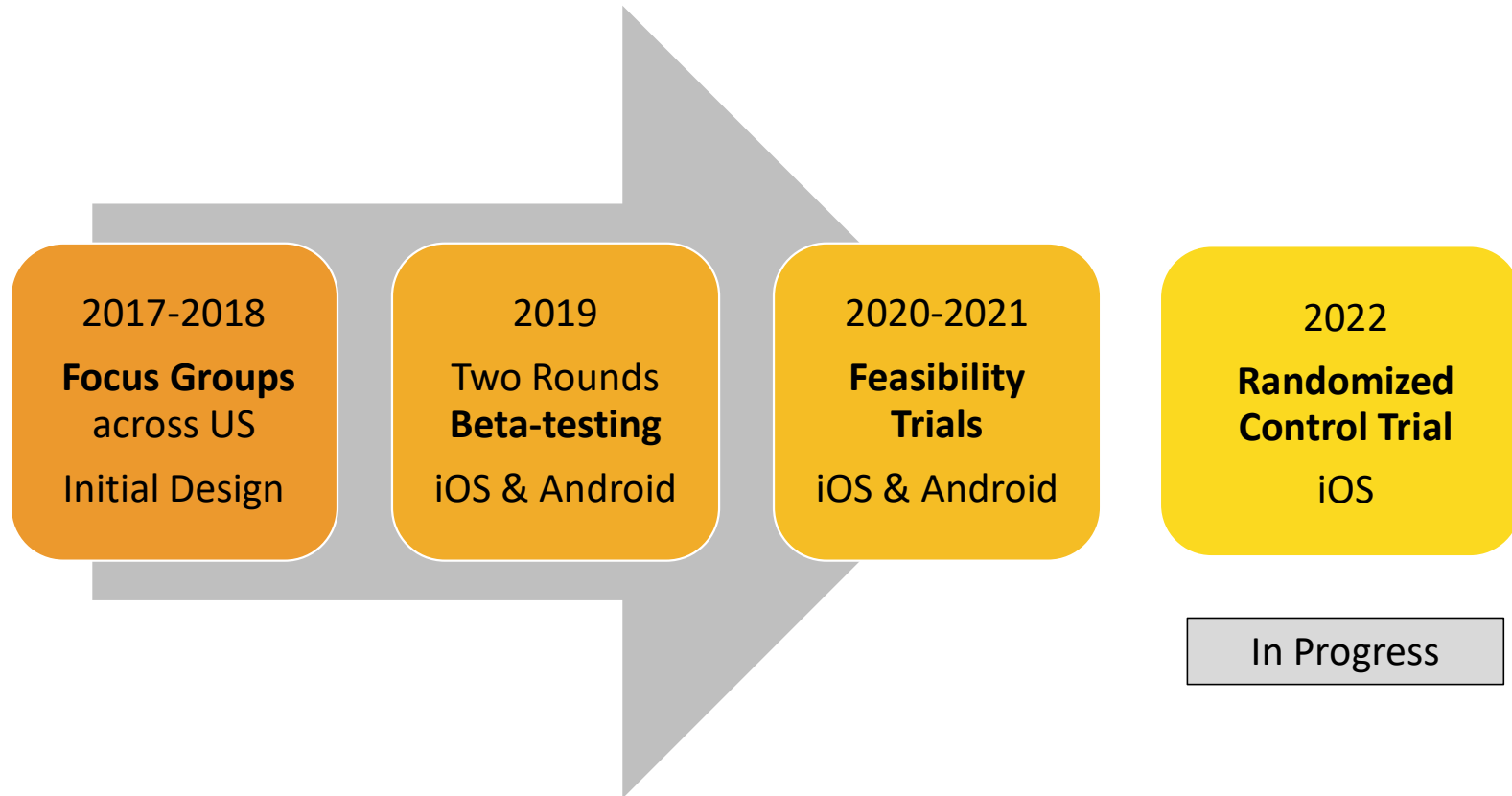
Family Forum

- Users share ideas, ask questions, get support
- Organized in sub-forums
- Moderated by trained peers

Library

- Lists of books, websites, other resources
- Optional fact sheets







**Participate in a focus
group to inform
new app for
mental health providers
to use with families**

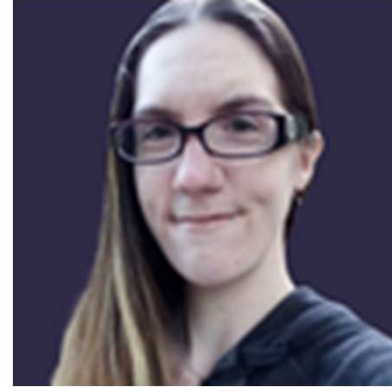
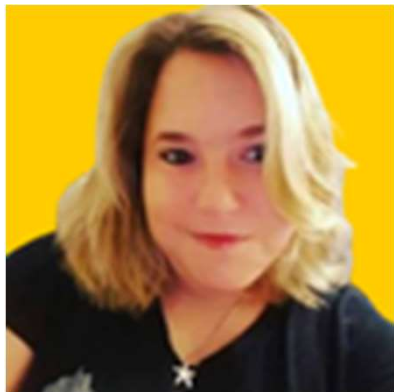
<https://bit.ly/Providerapp>

**Development of Provider-Assisted Families
Moving Forward Connect**



UNIVERSITY of
ROCHESTER
MEDICAL CENTER

MT.
HOPE
family center



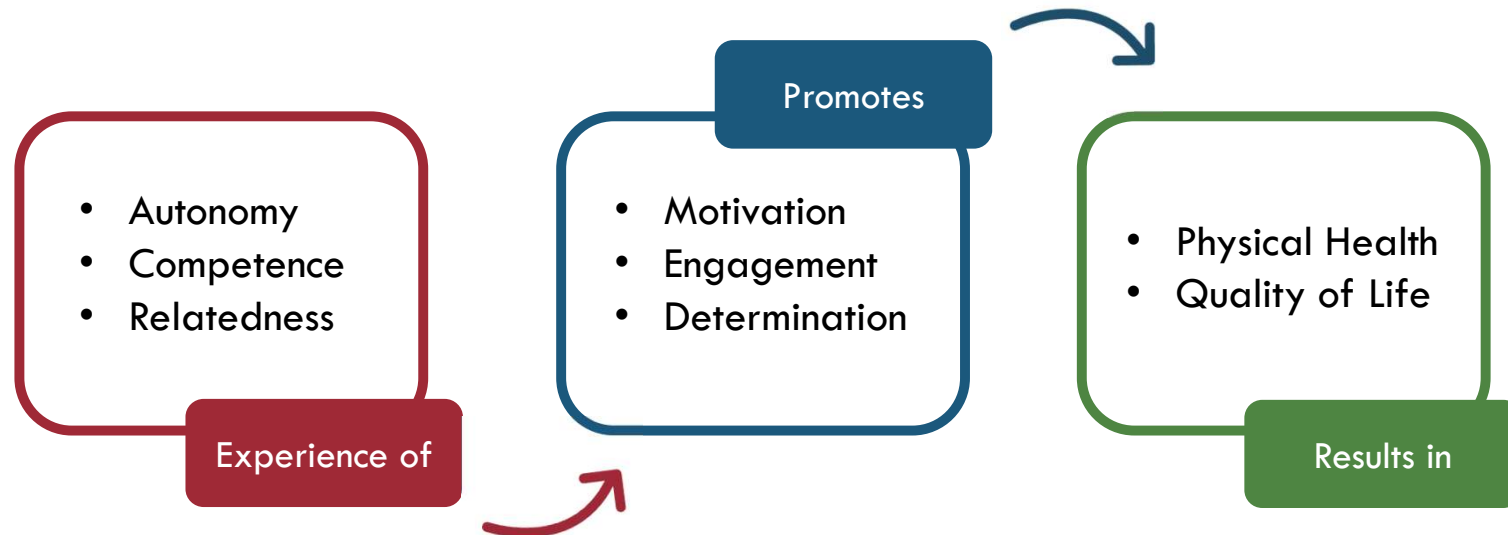
**PARTNERSHIP WITH THE ADULT LEADERSHIP COMMITTEE
OF FASD CHANGEMAKERS**

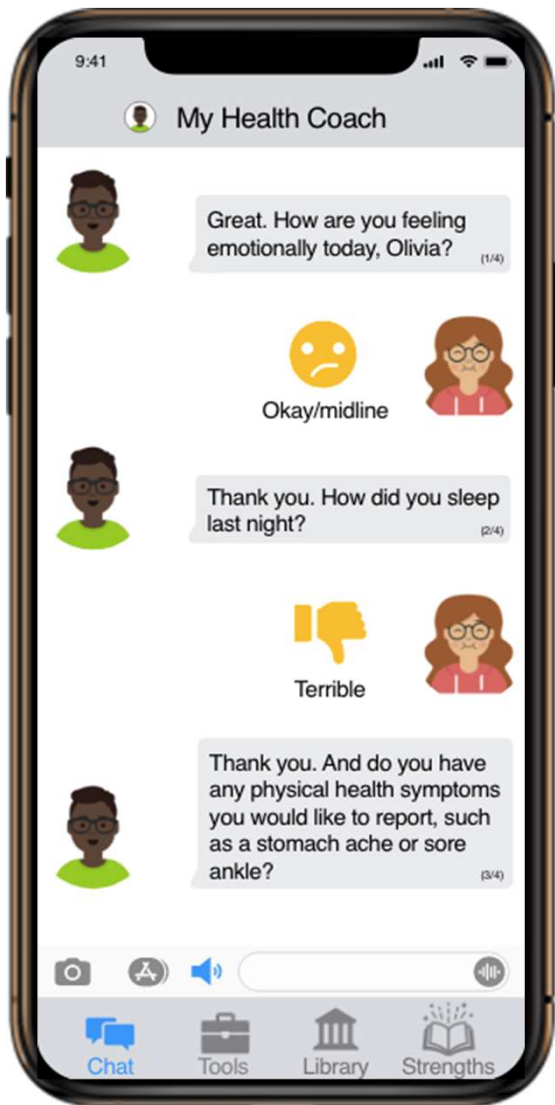
Inspiration for the My Health Coach app

- There is little attention and evidence-based supports for adults with FASD
- Our partners have documented significant physical health and quality of life concerns with their peers
 - Lay of the Land surveys 1 & 2
- “Nothing About Us Without Us”

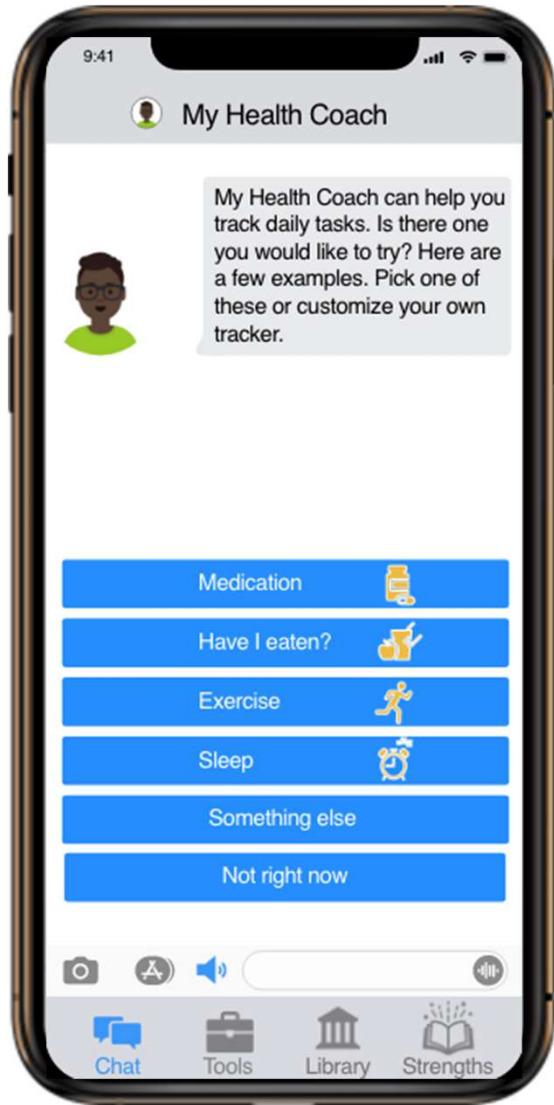


SELF-DETERMINATION THEORY FOR WELLNESS





Daily Check-in



General Tracker



Daily Message

SHARE YOUR THOUGHTS ON
APP DESIGNED FOR ADULTS WITH
FASD

PARTICIPATE IN ONLINE
SURVEY TODAY!
CLICK ON THE LINK TO BEGIN

CONNECT WITH US
TWITTER: @FASDCHANGEMAKRS & @CLPETRENKO
INSTAGRAM: @FASDCHANGEMAKRS.ALC
EMAIL: EMILY_SPEYBROECK@URMC.ROCHESTER.EDU

"DEVELOPING SMARTPHONE APPS FOR ADULTS WITH FASD"
UNIVERSITY OF ROCHESTER IN PARTNERSHIP WITH THE ADULT LEADERSHIP
COLLABORATIVE OF THE FASD CHANGEMAKERS

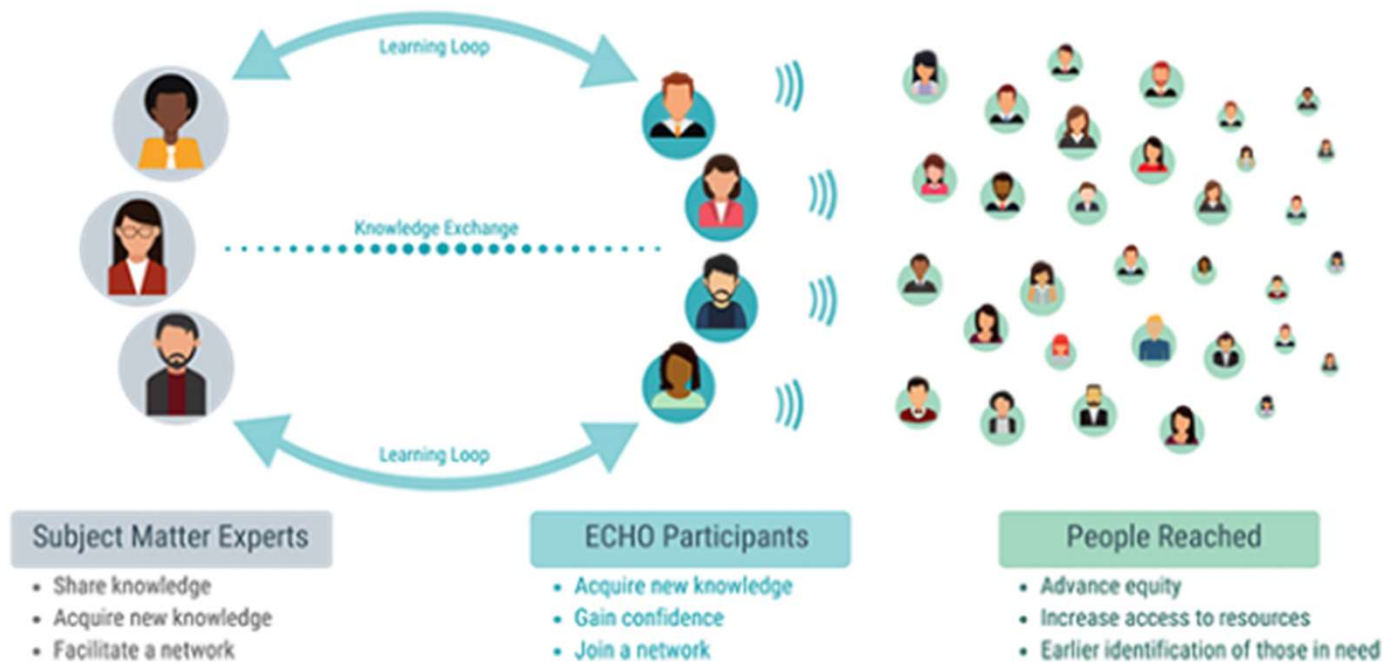
Who Can Participate?

Adults with FASD
or prenatal alcohol
exposure
anywhere in the
world

www.bit.ly/FASDApp

PROJECT ECHO© FASD (EXTENSION OF COMMUNITY HEALTHCARE OUTCOMES)

MOVING KNOWLEDGE, NOT PEOPLE



Thrive | Lifelong

Health • Research • FASD Supports

In September 2021, we have started a regular newsletter to keep you updated. This newsletter is applicable for parents, teachers, providers, researchers, friends and family, or anyone interested! Sign up and you'll receive highlights about new study results, progress updates, and alerts for research opportunities.

You can read current and past issues below. [Sign Up to Our Newsletter.](#)

Current Issue - January 2022

- Tip of the Month
- The FASD Collaborative Project
- FMF Connect Enrollment
- My Health Coach Enrollment
- Research Corner
- New Year's Resolutions Tips

Read



- Thank you to NIAAA and CIFASD for supporting this work
 - U01 AA026104
 - UH2 AA029050
- We also appreciate the generous support of Jay and Constance Mazelsky




Questions



Comments

Christie.Petrenko@Rochester.edu



Feedback

