

Equity-focused Dissemination & Implementation Webinar Series

| | |
|------------------------------------|--|
| November 1, 2022 4-5 PM EST | <u>Leveraging Technology and Community Engagement to Address Barriers to Care for People with Fetal Alcohol Spectrum Disorders</u> Christie Petrenko, Ph.D., URMIC. |
| November 8, 2022 3-4 PM EST | <u>Equity-Oriented Implementation Studies: Reflections from a Learner</u> Ana A. Baumann, Ph.D., Washington University School of Medicine |
| November 15, 2022 4-5 PM EST | <u>Advancing Quality Improvement with Implementation Science</u> Amy Tyler, M.D., M.S.C.S., University of Colorado |

MEDICINE *of* THE HIGHEST ORDER



CTSI
CLINICAL & TRANSLATIONAL
SCIENCE INSTITUTE

Leveraging Technology and Community Engagement to Address Barriers to Care for People with FASD Across the Lifespan

Christie Petrenko

Research Associate Professor
Director of Clinical Training
Mount Hope Family Center
Departments of Psychology & Pediatrics



Cristiano Tapparello

Research Associate Professor
Department of Electrical and Computer Engineering
Director of Software Engineering, URMH Health Lab



UNIVERSITY *of*
ROCHESTER

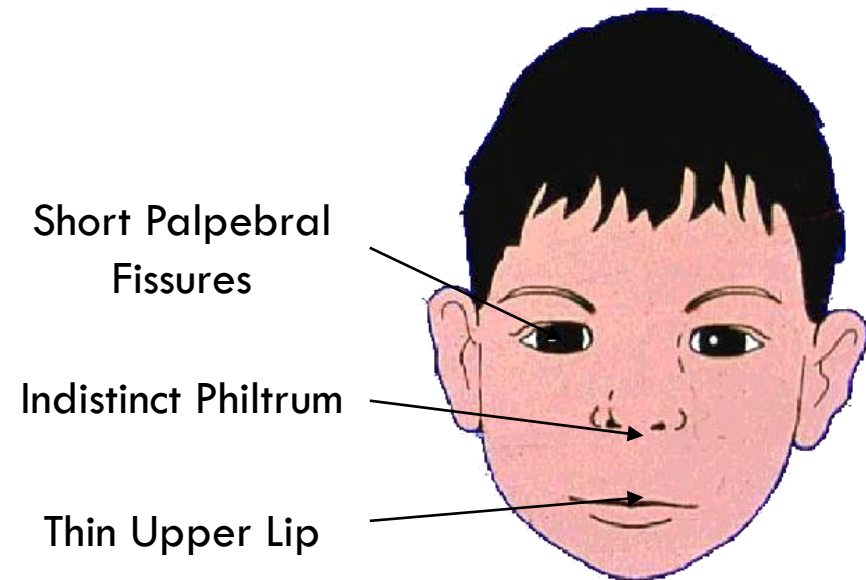
- Nothing to disclose

FETAL ALCOHOL SYNDROME (FAS)

- 1) Characteristic facial features
- 2) Pre- and/or post-natal growth deficiency
- 3) Deficient brain growth, seizures, or structural abnormalities
- 4) Neurobehavioral impairment

Prevalence: 6-9 out of 1000 live births

Discriminating Facial Features



FAS IS ONLY THE TIP OF THE ICEBERG!

FETAL ALCOHOL SPECTRUM DISORDERS (FASD):

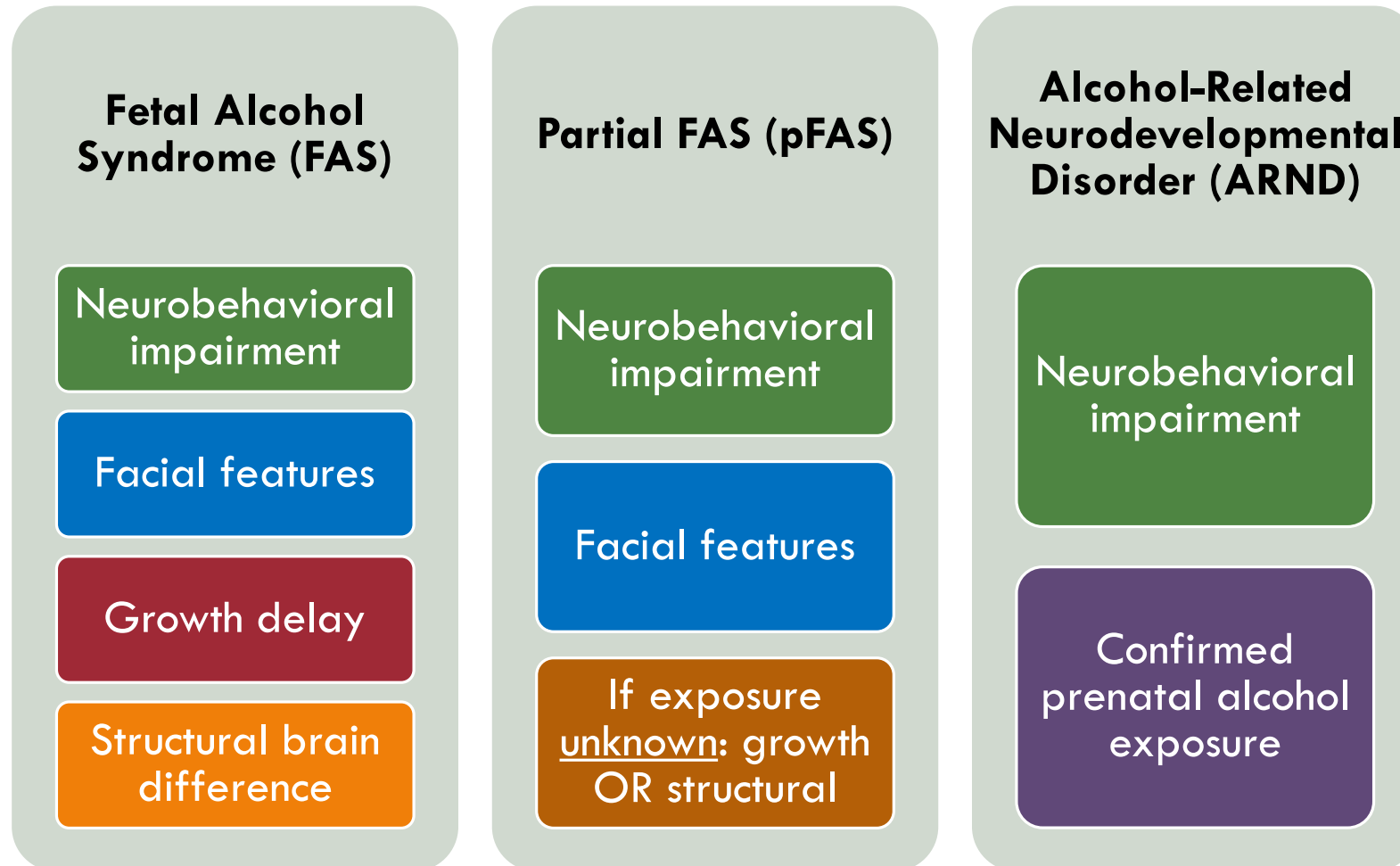
- **NOT** a diagnostic term
- Umbrella term used to describe the range of outcomes resulting from alcohol exposure during pregnancy.

Death, SIDS

isolated effects;
cognitive
abnormalities

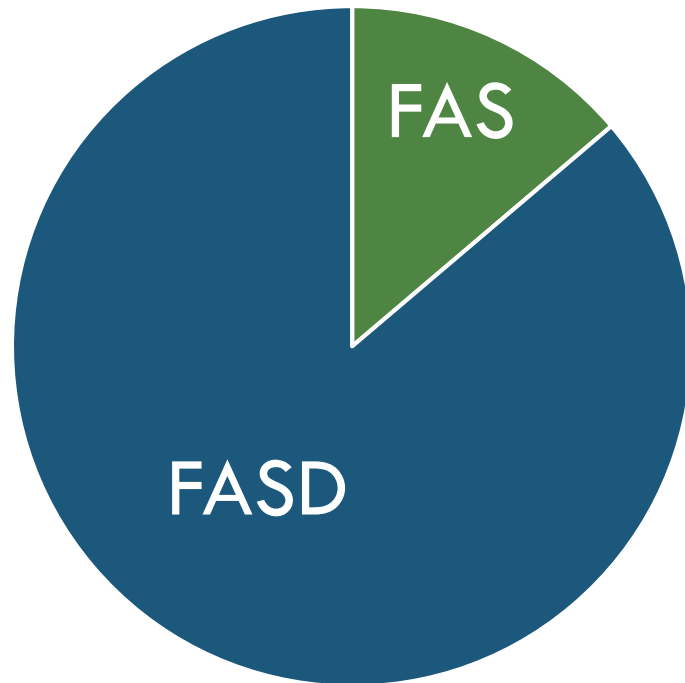


FETAL ALCOHOL SPECTRUM DISORDERS (FASD)



PREVALENCE OF FASD

1.1 to 5.0% in U.S.



SPECIAL POPULATIONS

Compared to the global FASD prevalence:

- 5 to 68 times higher for children in care
- 16 to 25 times higher for Aboriginal populations
- 19 times higher in psychiatric population
- 24 times higher in a lower SES population
- 30 times higher in a correctional population



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

STIGMA

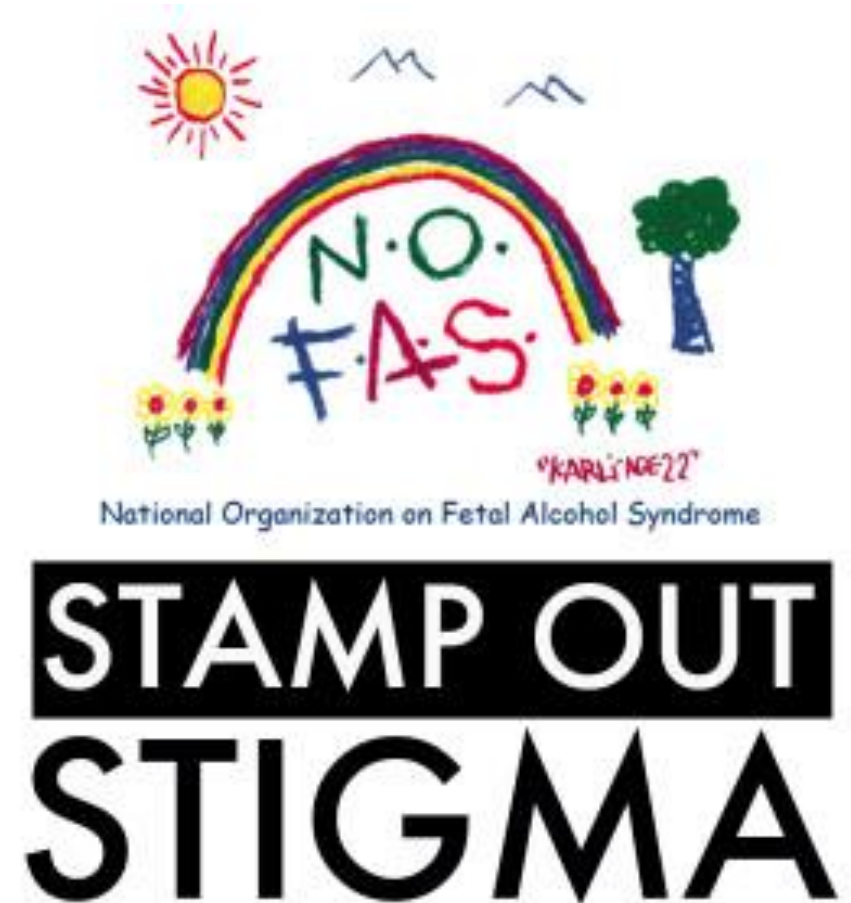
Public stigma is pervasive and severe

Internalized self-stigma, shame, guilt

Contributes to under-diagnosis and low access to services

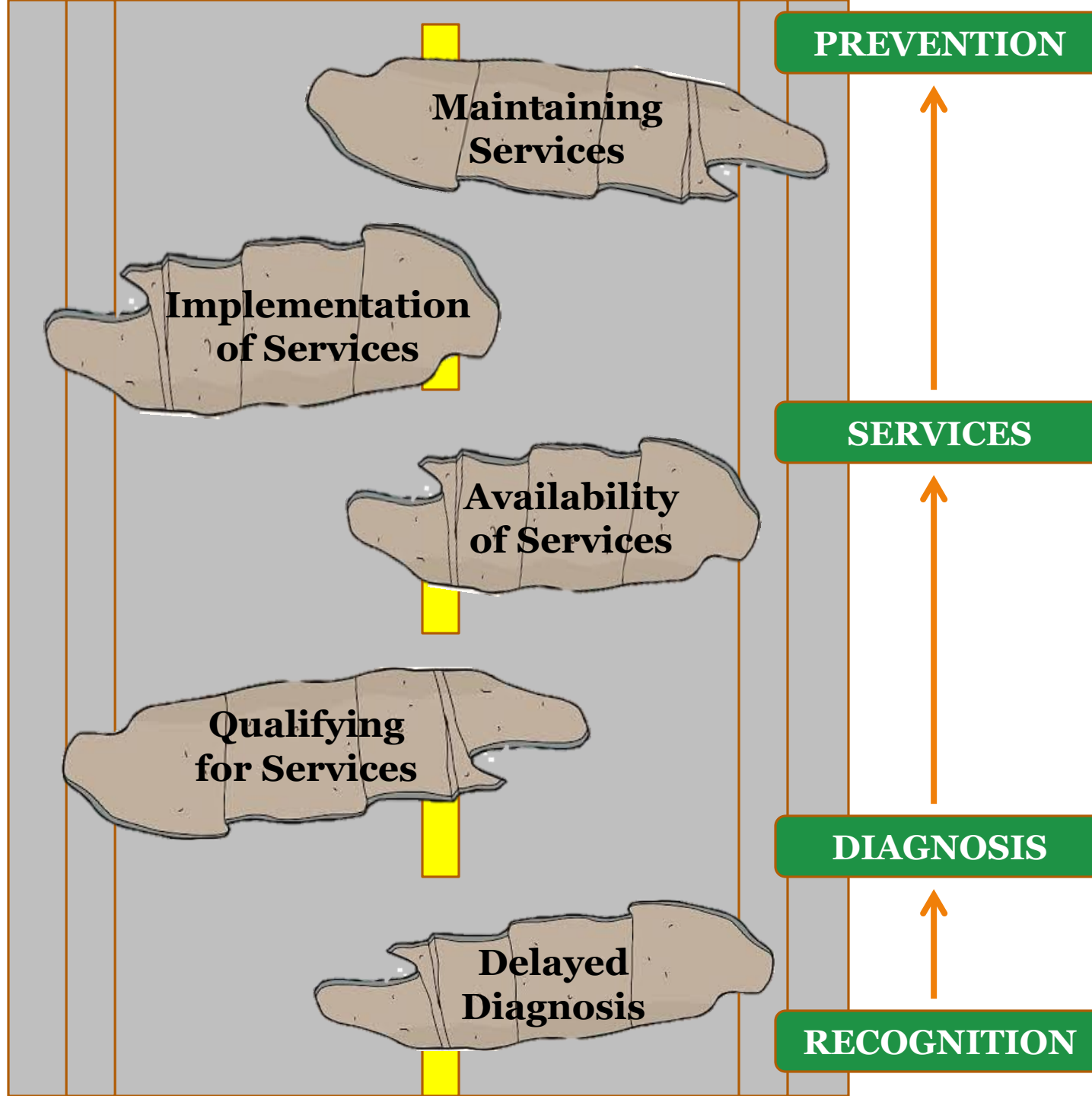
- Mothers uncomfortable talking about PAE or seeking supports
- Providers not asking about PAE; afraid to label a child with FASD

People with FASD feeling “less than”



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

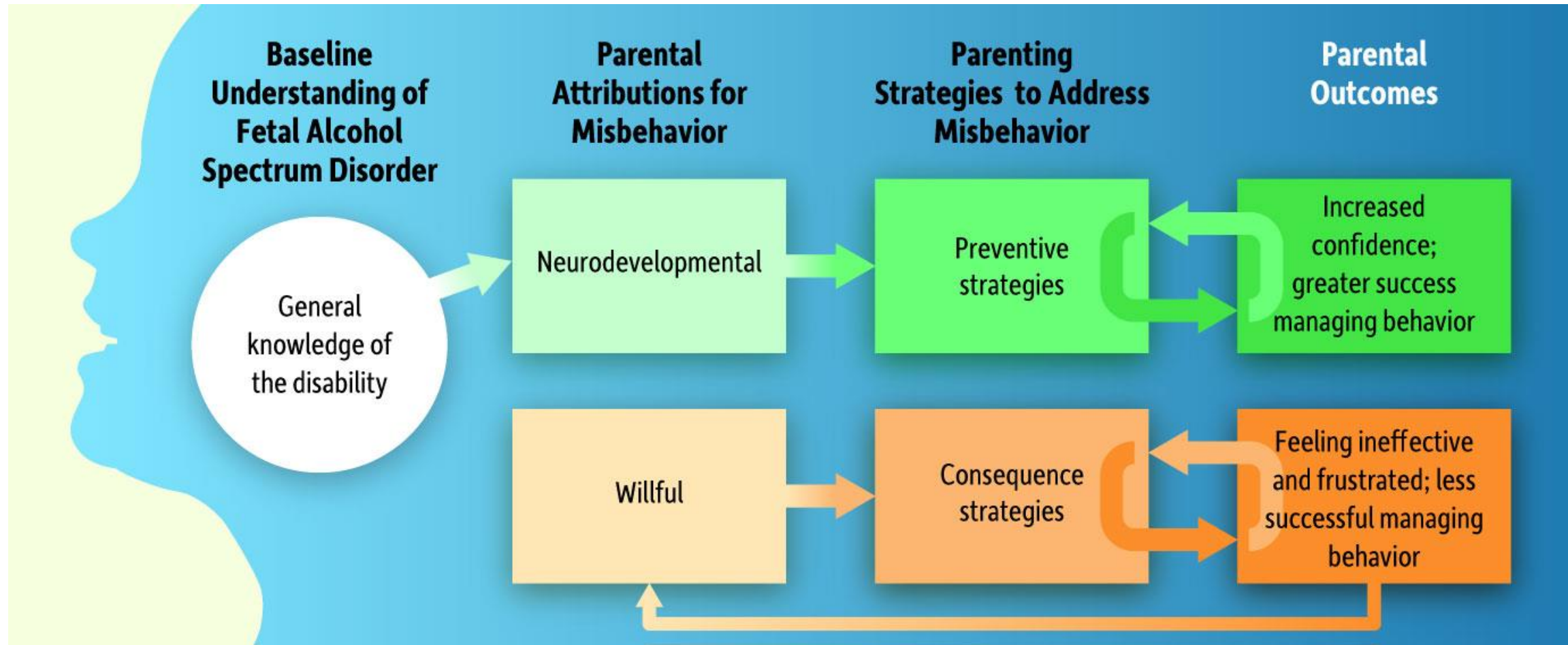
Lack of Knowledge of FASD



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

Petrenko et al., 2014

FASD SYMPTOMS ARE EASILY MISUNDERSTOOD



FEELING DIFFERENT

Awareness of difficulties → limiting

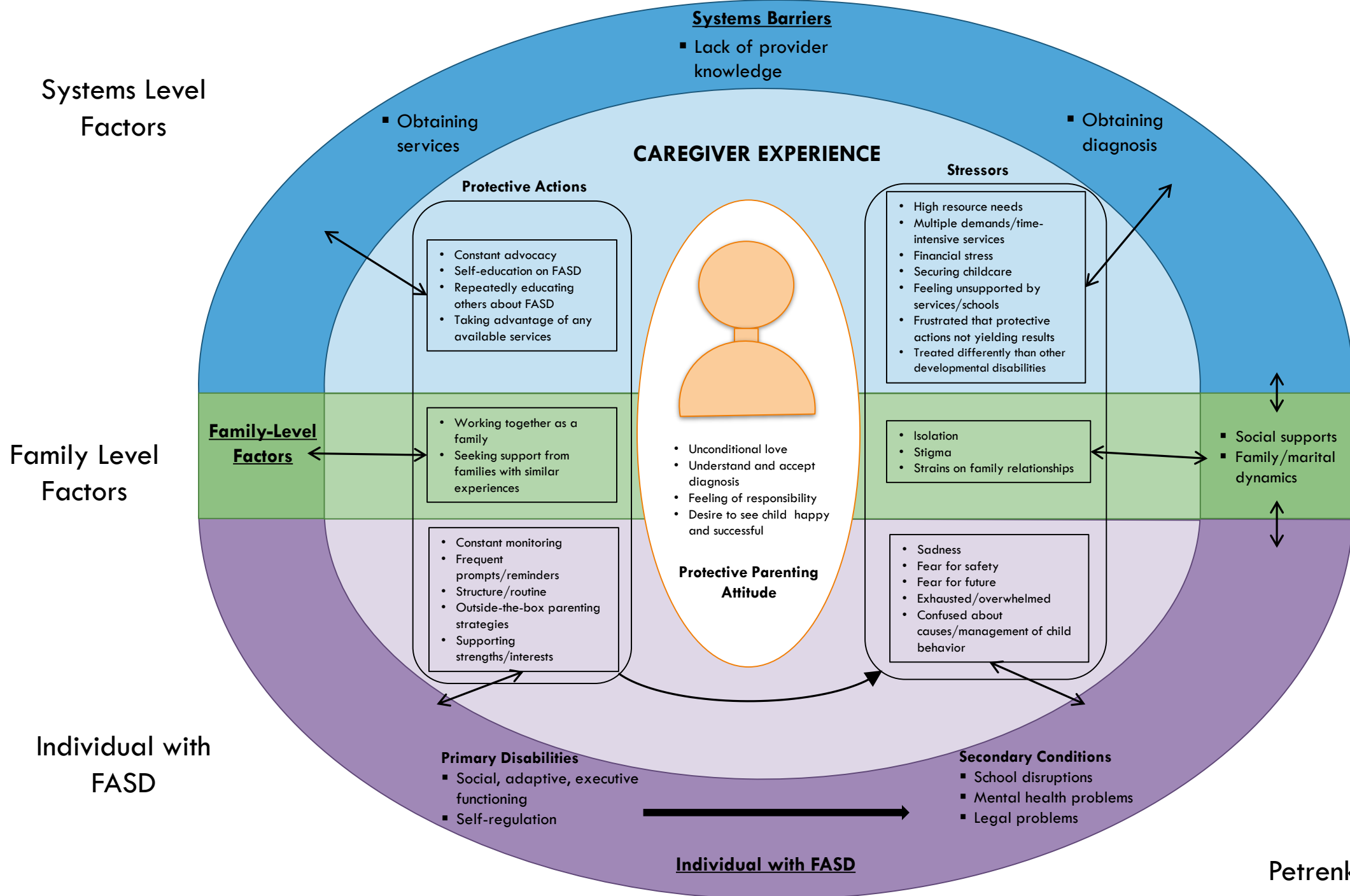
Under-supported, discrimination

FASD feels unfair

Difficulty coping

Persistence







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.



So how do we increase access at any kind of scale when there are so many barriers?

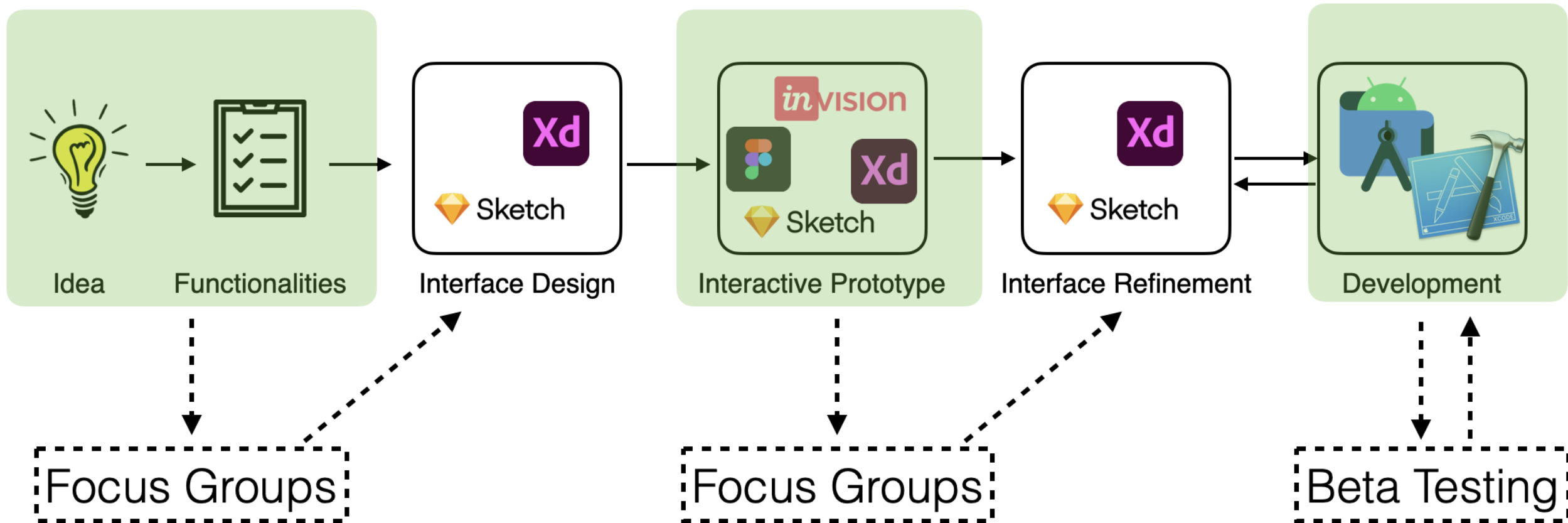
The Possibilities of Mobile Health (mHealth)

- More than 83% of adults worldwide own a smartphone
- 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



Our General mHealth App Development Process

Involve key stakeholders

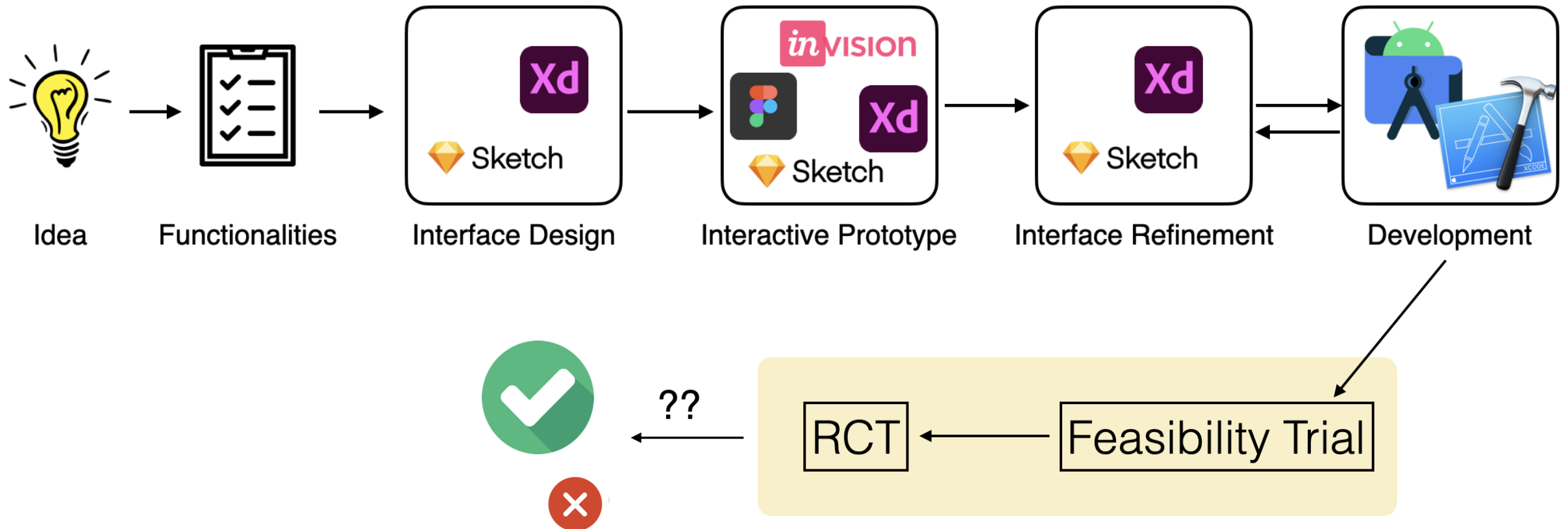


Our General mHealth App Development Process

- Cross-platform (iOS, Android) and cloud-based
- HIPAA compliance to ensure privacy and security
- Based on state of the art products for app development
 - Amazon Web Services
 - Apple ResearchKit and CareKit
 - ResearchStack and ManageMyCondition



Our General mHealth App Development Process

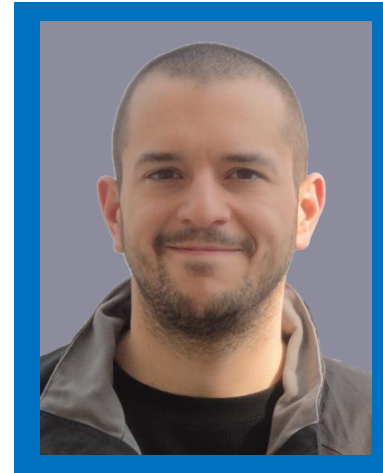




Heather Carmichael Olson, Ph.D.
SCRI / U. of Washington



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



Cristiano Tapparello, Ph.D.
U. of Rochester



Wendi Heinzelman, Ph.D.
U. of Rochester



Carson Kautz
MHFC / U. of Rochester



Alicia Roth
MHFC / U. of Rochester



Shuo Zhang
MHFC / U. of Rochester



Zhiyao Duan, Ph.D.
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

FMF Connect Components

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

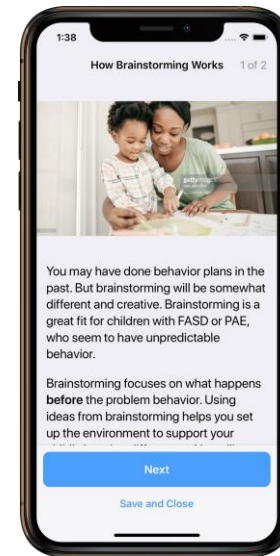
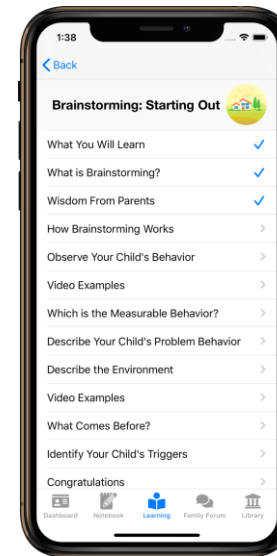
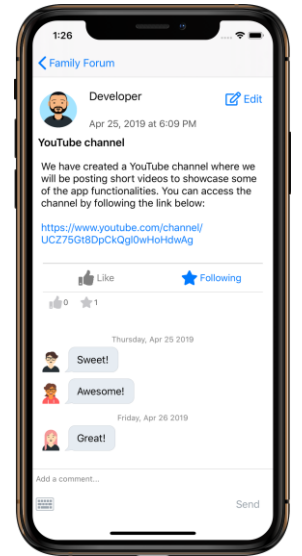
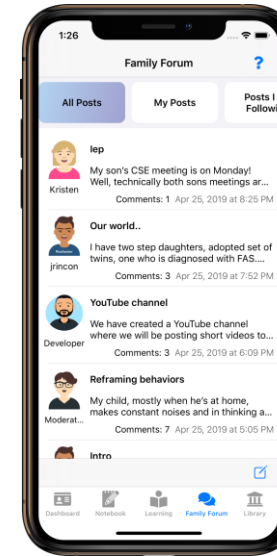
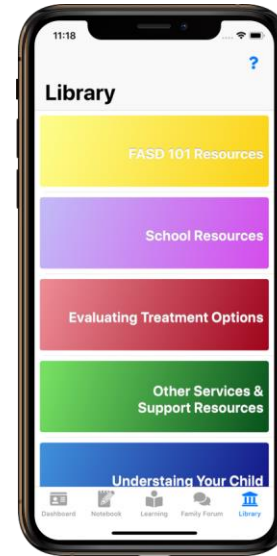
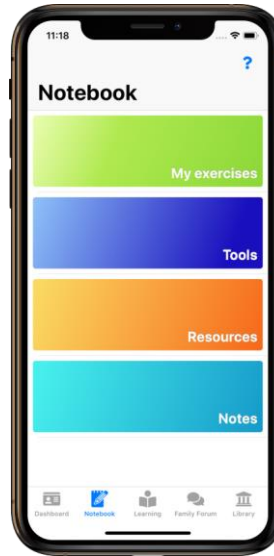
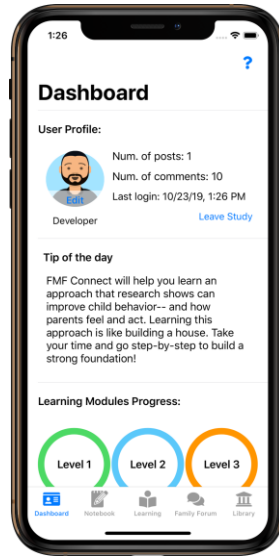
- Users share ideas, ask questions, get support
- Organized in sub-forums
- Moderated by trained peers

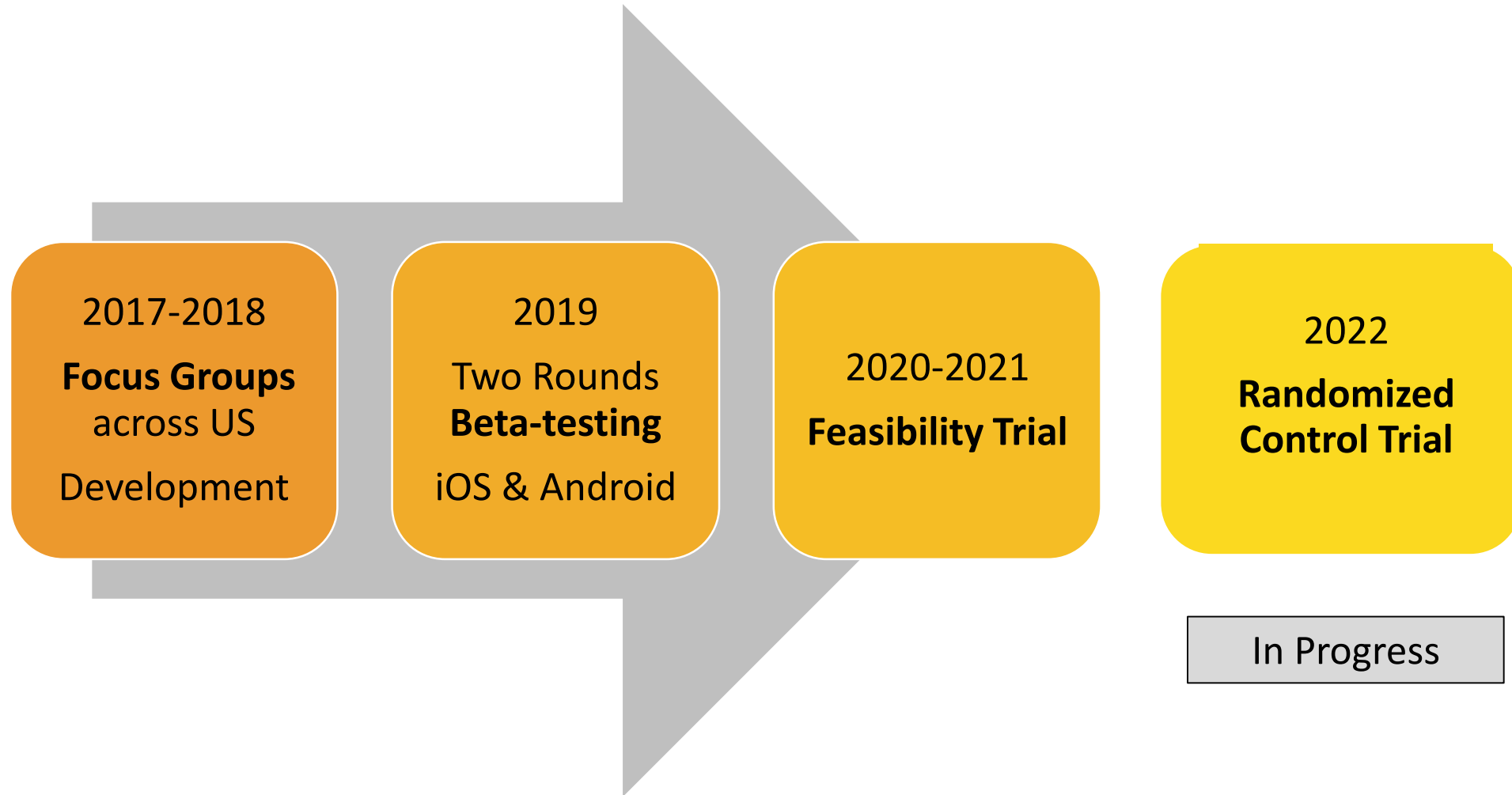
Library

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

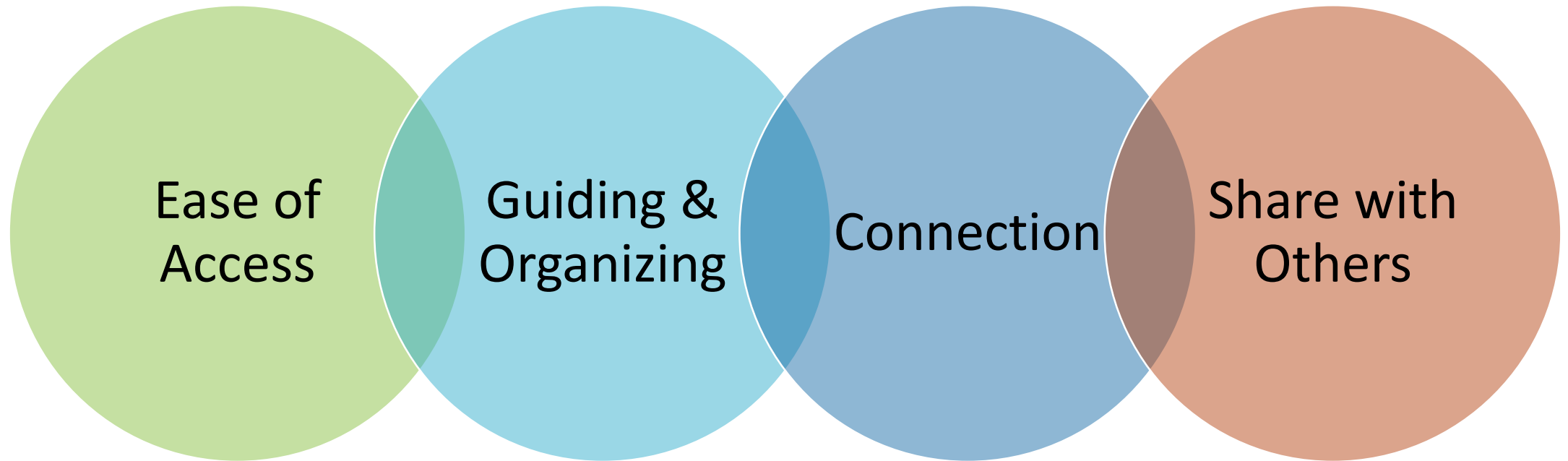


FMF Connect Screenshots





Overall Positive App Features/Aspects



Petrenko et al., 2019

Two Rounds of Beta Testing (2019)

- 1st Round (Summer)

- 📍 21 Parents /18 Providers

- iOS only

- 2nd Round (Winter)

- 📍 25 Parents /1 Provider

- iOS and Android

- Data Collection

- Focus groups and interviews
 - Data collected in app



Petrenko et al., 2021

App Distribution & Usability



39 parents and 16 providers installed and used the app across both tests



Ability to track bugs/crashes in real time

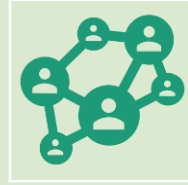


Released 5 updates to fix bugs and expand functionalities



Collected analytics to evaluate level of engagement to different app components

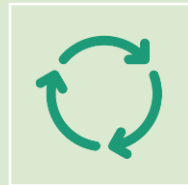
Feasibility Pilot Trial Objectives



Intervention Feasibility



Trial Feasibility



Caregiver Implementation

Feasibility Trial: Recruitment



iOS



Android



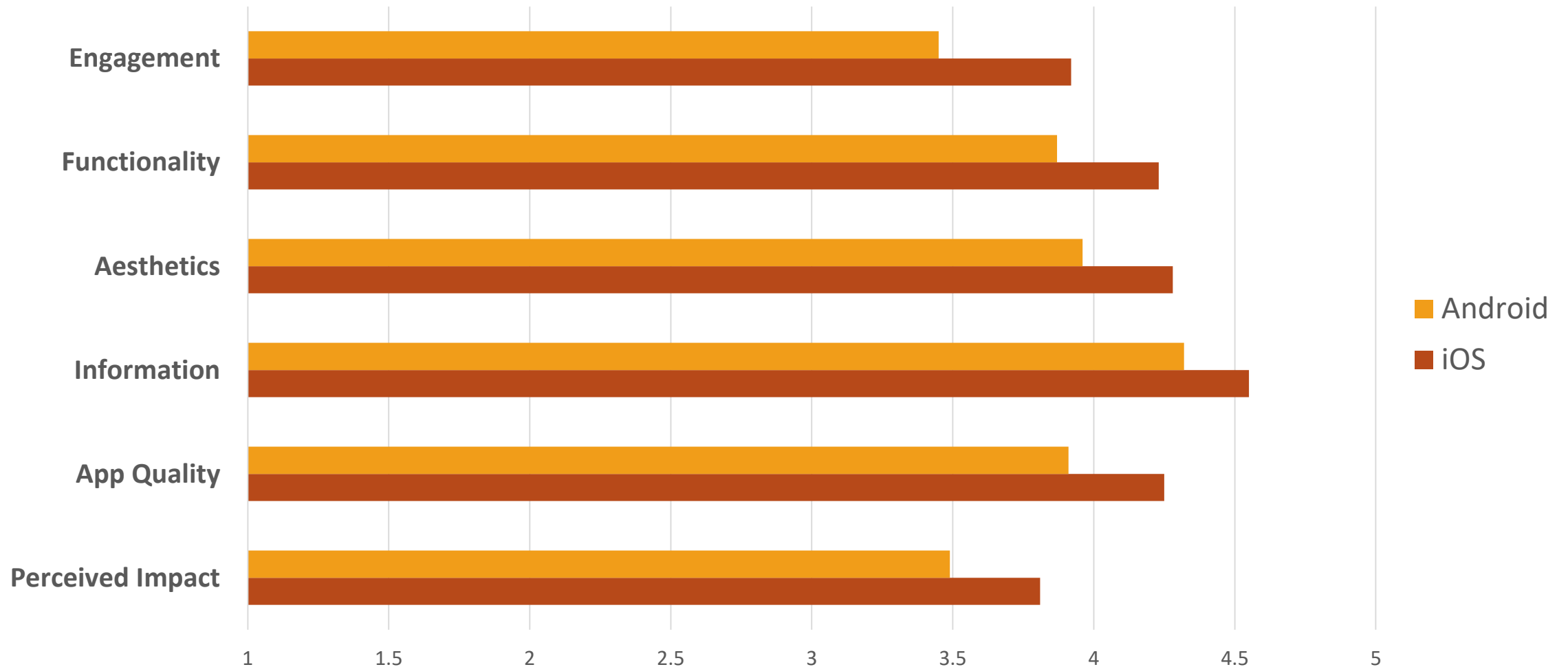
iOS – stable

- Beta-test 1 (April – May 2019)
- Beta-test 2 (Nov – Dec 2019)
- Feasibility trial (March – Sept 2020)

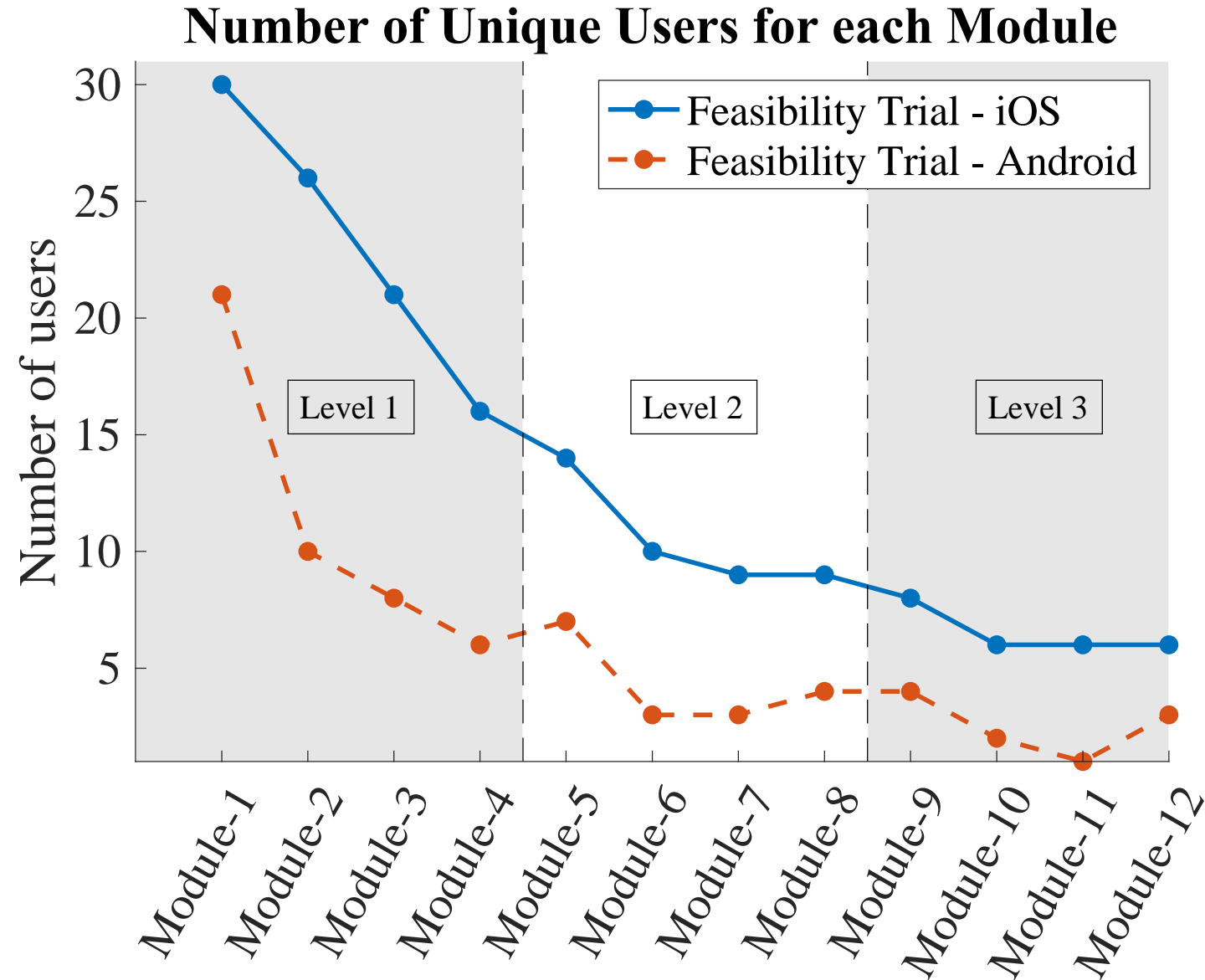
Android – more issues

- Beta-test 2 (Nov – Dec 2019)
- Current feasibility trial (Feb – July 2021)

Mean Scores on uMARS (out of 5)

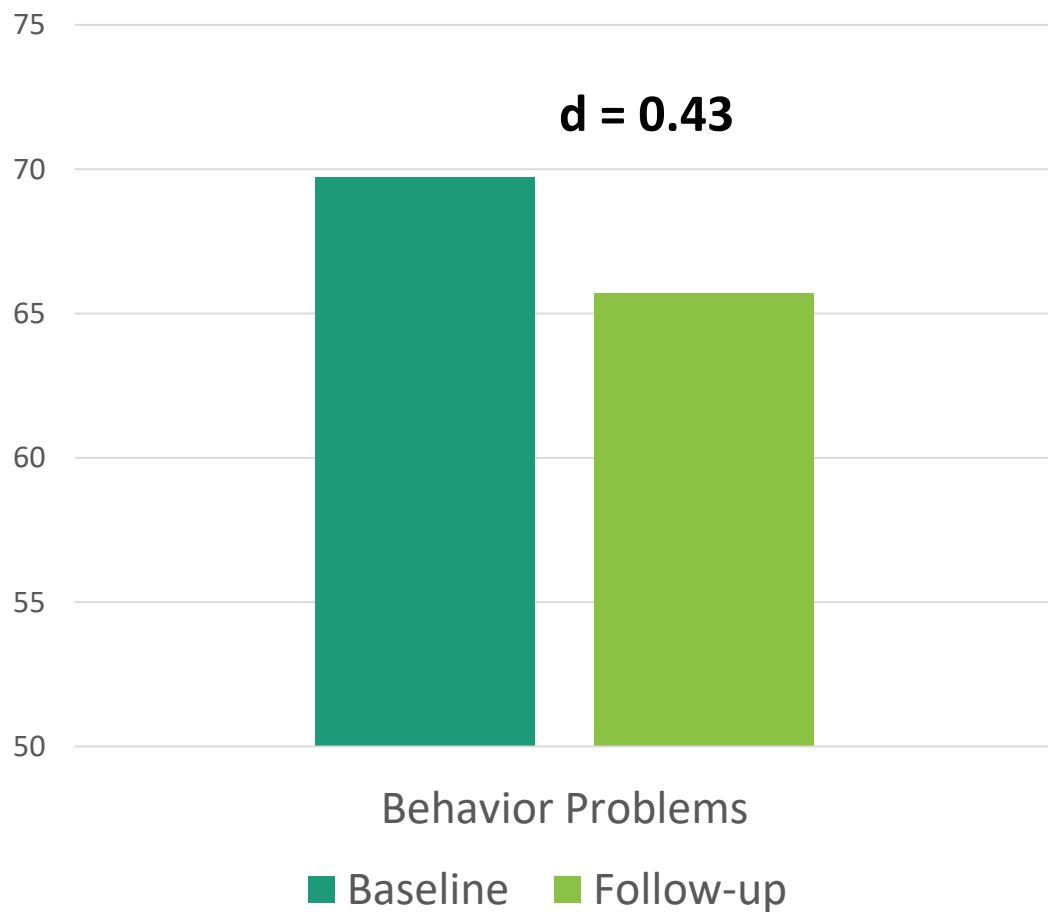


Feasibility Trial: Learning Module Completion

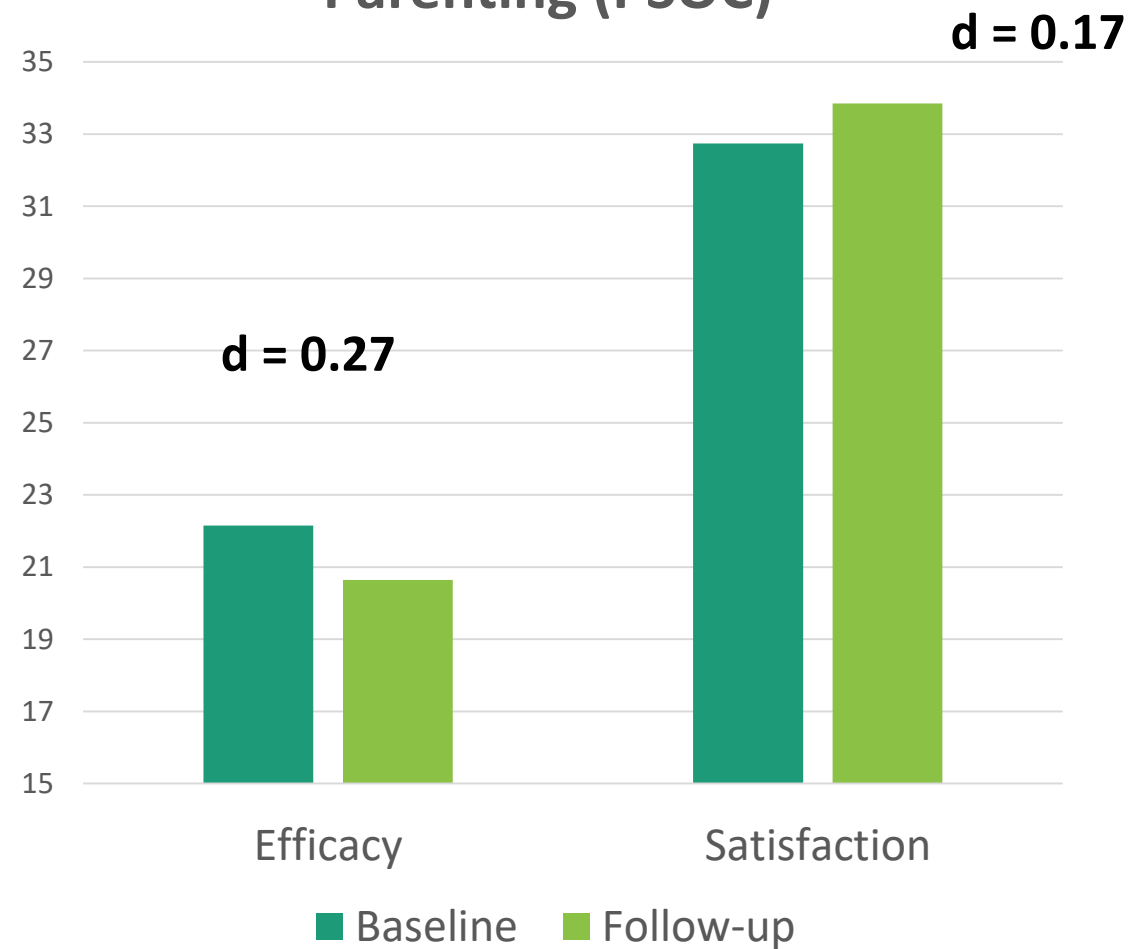


Outcome Data Before & After Receiving App

Behavior Problems (ECBI)

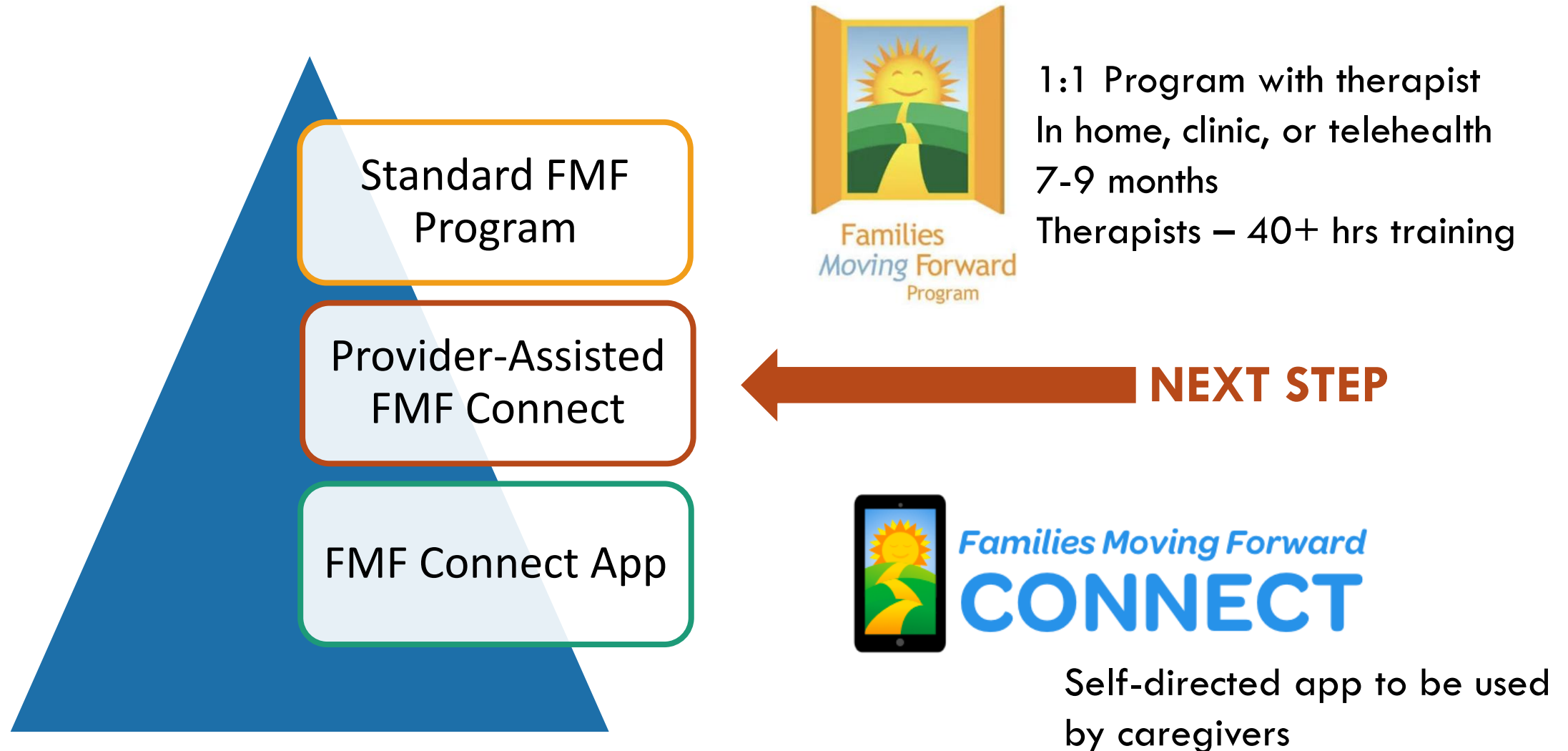


Parenting (PSOC)



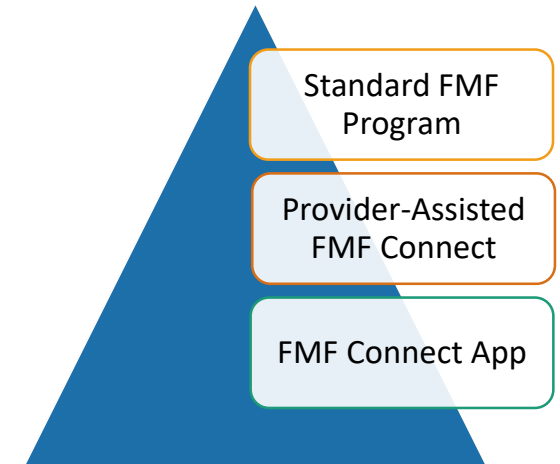
Advancing this Approach to Systems of Care

Childhood: Building a Continuum of Care



Rationale for Provider-Assisted FMF Connect

- Most people with FASD go undiagnosed
- Goal to increase screening/diagnosis in mental health settings
- Providers more likely to screen/diagnose when have something to provide/support family
- Some caregivers like to do FMF Connect on their own, some prefer full FMF Program with specialist (7-9mo), and others are somewhere in the middle
 - we are trying to define what middle looks like



A photograph of two women sitting at a table in a bright room with large windows. One woman, with curly hair and wearing a white top, is looking towards the other woman, whose back is to the camera. They appear to be in a professional or collaborative meeting.

**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**



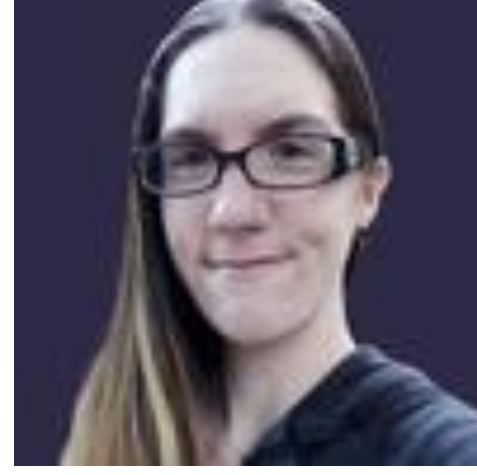
UNIVERSITY of
ROCHESTER
MEDICAL CENTER

Mt.
HOPE
family center

- April-May 2021: completed 23 interviews with teachers
- Using ADAPT-ITT framework
- Needs Assessment themes:
 - Theme 1: Teachers have very limited time
 - Theme 2: There are very few FASD-informed resources
 - Theme 3: General and special education teachers have different needs
- Engaging an Advisory Board of Teachers to inform adaptation of FMF Connect



Carson Kautz-Turnbull
5th Year Graduate Student
MHFC / U. of Rochester



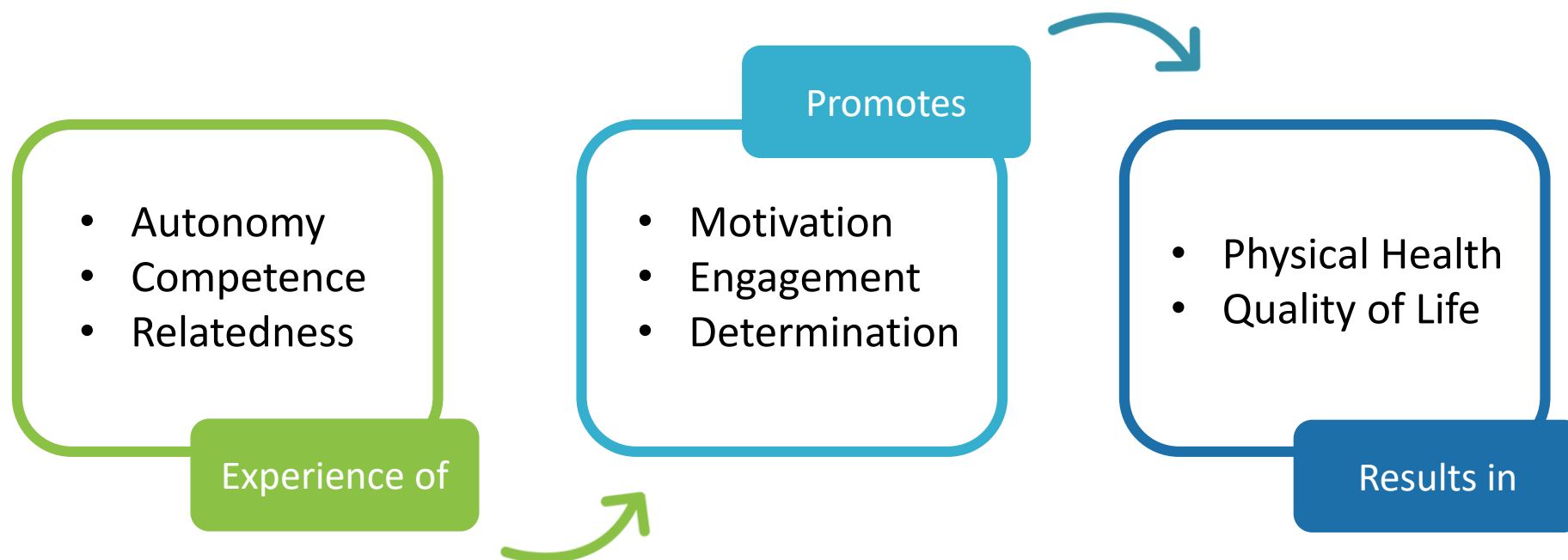
**MY HEALTH COACH: PARTNERSHIP WITH THE ADULT
LEADERSHIP COLLABORATIVE OF FASD CHANGEMAKERS**



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”

Theoretical Model: Self-Determination



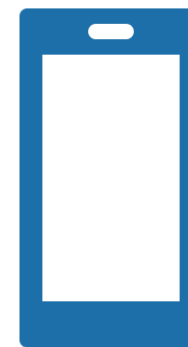
Aim 1: Development



**Regular meetings with
ALC FASD Changemakers
in Advisory Board**



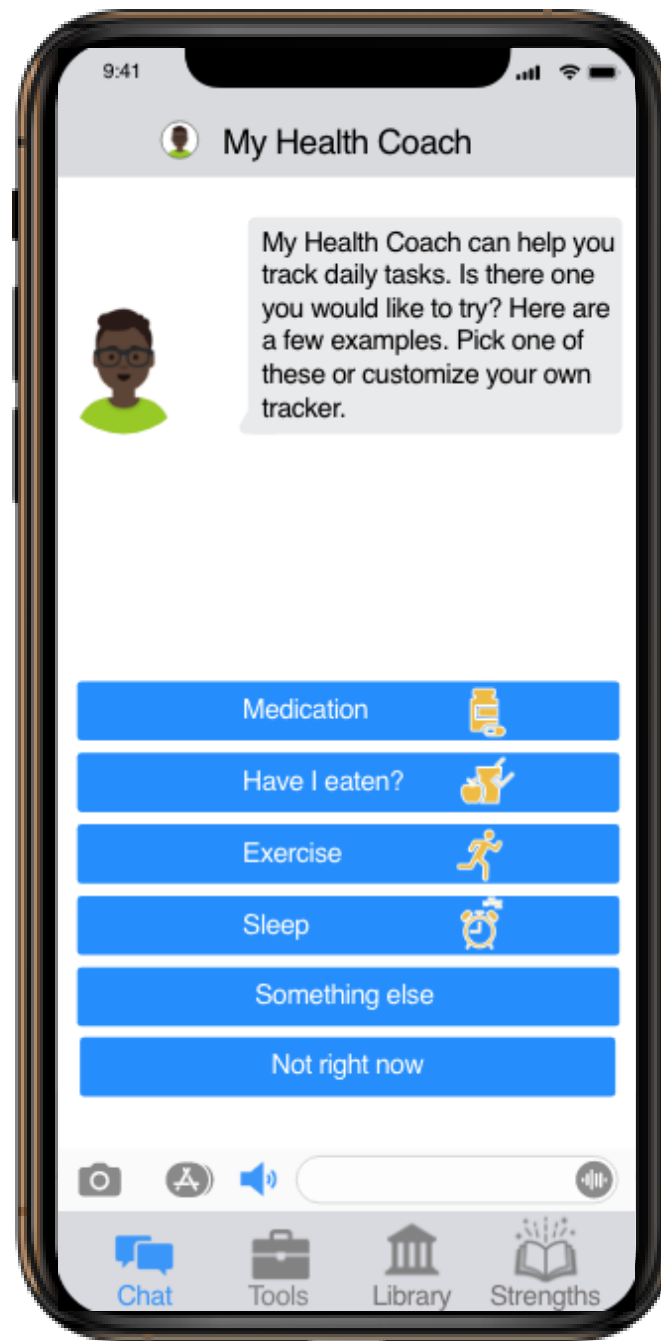
Focus Groups
with Adults with FASD
ALC members led data collection



Online Survey
Reach broader range of adults to
refine design and content features
Build on experience and network
of ALC members



Daily Check-in

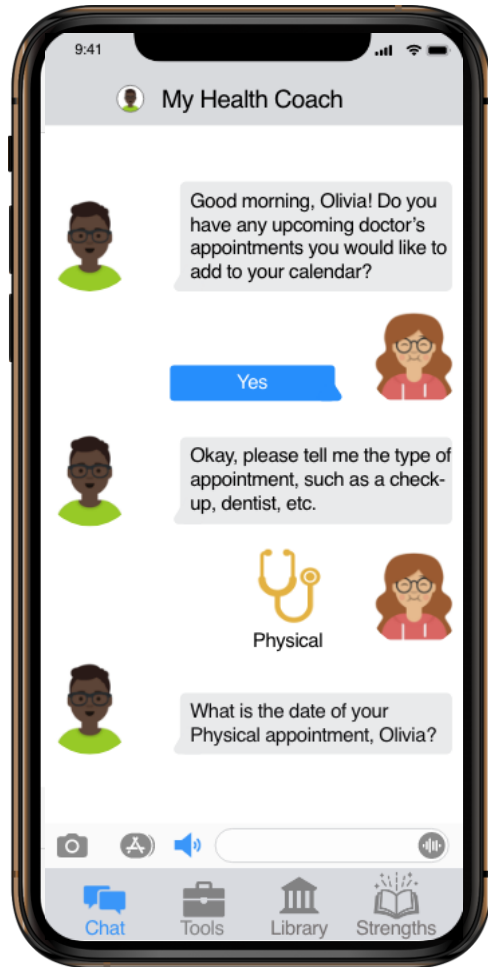


General Tracker



Daily Message

Aim 2: Feasibility Study (2023)



- Pilot Feasibility Trial (40 people)
- After 6 weeks, we will look at how well the app helps with:
 - Well-being and self determination
 - Self-management
 - Self-advocacy
 - Social support

Also:

- User satisfaction
- Patterns of app use

- 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

