## Equity-focused Dissemination & Implementation Webinar Series

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Speaker and Affiliation</th>
</tr>
</thead>
<tbody>
<tr>
<td>November 1, 2022</td>
<td>Leveraging Technology and Community Engagement to Address Barriers to Care for People with Fetal Alcohol Spectrum Disorders</td>
<td>Christie Petrenko, Ph.D., URMC.</td>
</tr>
<tr>
<td>November 8, 2022</td>
<td>Equity-Oriented Implementation Studies: Reflections from a Learner</td>
<td>Ana A. Baumann, Ph.D., Washington University School of Medicine</td>
</tr>
<tr>
<td>November 15, 2022</td>
<td>Advancing Quality Improvement with Implementation Science</td>
<td>Amy Tyler, M.D., M.S.C.S., University of Colorado</td>
</tr>
</tbody>
</table>
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, URMC Health Lab
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

Hoyme et al., 2016; May et al., 2014
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)

Fetal Alcohol Syndrome (FAS)
- Neurobehavioral impairment
- Facial features
- Growth delay
- Structural brain difference

Partial FAS (pFAS)
- Neurobehavioral impairment
- Facial features
- If exposure unknown: growth OR structural

Alcohol-Related Neurodevelopmental Disorder (ARND)
- Neurobehavioral impairment
- Facial features
- Confirmed prenatal alcohol exposure

Hoyme et al., 2016
PREVALENCE OF FASD

1.1 to 5.0% in U.S.

May et al., 2018
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

Popova et al., 2019
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
What are the Barriers to Supporting People with FASD?

Lack of Knowledge of FASD

- Qualifying for Services
- Availability of Services
- Implementation of Services
- Maintaining Services

Petrenko et al., 2014
FAFD SYMPTOMS ARE EASILY MISUNDERSTOOD

Petrenko et al., 2016
FEELING DIFFERENT

- Awareness of difficulties → limiting
- Under-supported, discrimination
- FASD feels unfair
- Difficulty coping
- Persistence

Domeij et al., 2018
Unconditional love
Understand and accept diagnosis
Feeling of responsibility
Desire to see child happy and successful

Protective Parenting Attitude

Protective Actions
- Constant advocacy
- Self-education on FASD
- Repeatedly educating others about FASD
- Taking advantage of any available services

Stressors
- High resource needs
- Multiple demands/time-intensive services
- Financial stress
- Securing childcare
- Feeling unsupported by services/schools
- Frustrated that protective actions not yielding results
- Treated differently than other developmental disabilities

Family-Level Factors
- Working together as a family
- Seeking support from families with similar experiences
- Constant monitoring
- Frequent prompts/reminders
- Structure/routine
- Outside-the-box parenting strategies
- Supporting strengths/interests

Primary Disabilities
- Social, adaptive, executive functioning
- Self-regulation

Secondary Conditions
- School disruptions
- Mental health problems
- Legal problems

Social supports
Family/marital dynamics

Individual with FASD

Petrenko et al., 2019
PEOPLE WITH FASD HAVE IMPORTANT STRENGTHS

Kautz-Turnbull et al., 2022
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?
• 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

Idea → Functionalities

Focus Groups

Interface Design

Xd Sketch

Focus Groups

Interactive Prototype

Xd Sketch

Interface Refinement

Xd Sketch

Development

Beta Testing
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
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
Learning Modules
• 12 core modules, 3 levels
• Educational text/audio
• Exercises to practice content
• Animation and video

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

Notebook
• User builds personalized section for later reference
• Exercises about child, selected content, tools, notes
FMF Connect Screenshots
2017-2018 Focus Groups across US Development

2019 Two Rounds Beta-testing iOS & Android

2020-2021 Feasibility Trial

2022 Randomized Control Trial

In Progress
Focus Groups Findings: Global Impressions

Overall Positive App Features/Aspects

- Ease of Access
- Guiding & Organizing
- Connection
- Share with Others

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
Intervention Feasibility: Technology

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)
Mobile Application Rating Scale: User Version (uMARS)

Mean Scores on uMARS (out of 5)

- **Engagement**
- **Functionality**
- **Aesthetics**
- **Information**
- **App Quality**
- **Perceived Impact**

<table>
<thead>
<tr>
<th>Category</th>
<th>Android</th>
<th>iOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engagement</td>
<td>3.7</td>
<td>4.0</td>
</tr>
<tr>
<td>Functionality</td>
<td>3.9</td>
<td>4.1</td>
</tr>
<tr>
<td>Aesthetics</td>
<td>3.9</td>
<td>4.1</td>
</tr>
<tr>
<td>Information</td>
<td>4.3</td>
<td>4.5</td>
</tr>
<tr>
<td>App Quality</td>
<td>4.0</td>
<td>4.2</td>
</tr>
<tr>
<td>Perceived Impact</td>
<td>3.8</td>
<td>4.0</td>
</tr>
</tbody>
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Feasibility Trial: Learning Module Completion

Number of Unique Users for each Module

- Feasibility Trial - iOS
- Feasibility Trial - Android

Number of users:
- Level 1
- Level 2
- Level 3

Modules:
- Module-1
- Module-2
- Module-3
- Module-4
- Module-5
- Module-6
- Module-7
- Module-8
- Module-9
- Module-10
- Module-11
- Module-12
Outcome Data Before & After Receiving App

Behavior Problems (ECBI)
- Baseline: 70
- Follow-up: 50
  - d = 0.43

Parenting (PSOC)
- Efficacy: 21
- Satisfaction: 31
  - d = 0.27
  - d = 0.17
Advancing this Approach to Systems of Care
Childhood: Building a Continuum of Care

1:1 Program with therapist
In home, clinic, or telehealth
7-9 months
Therapists – 40+ hrs training

NEXT STEP

Standard FMF Program
Provider-Assisted FMF Connect
FMF Connect App

Self-directed app to be used by caregivers
• 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
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

- Autonomy
- Competence
- Relatedness

Experience of

Promotes

- Motivation
- Engagement
- Determination

Results in

- Physical Health
- Quality of Life

Ryan & Deci, 2000
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
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

Feedback

Christie.Petrenko@Rochester.edu