Attendees will be able to:

- State how a mobile health intervention could reduce barriers and increase access to FASD-informed care
- Describe key features of the FMF Connect App
- Evaluate the presentation of the FMF Connect Prototype and consider their opinions of the development process and app features
Christie Petrenko and Cristiano Tapparello have no conflicts of interest to report.
Families Moving Forward
Connect: Developing a Mobile Health Intervention for Families Raising Children with FASD

Christie L. M. Petrenko, Ph.D. & Cristiano Tapparello, Ph.D.
CIFASD Plenary
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

Jenn Parr  
MHFC / U. of Rochester

Zhiyao Duan, Ph.D.  
U. of Rochester

Jordan Floyd  
U. of Rochester
Barriers to FASD-Informed Care
So how do we make it easier for more families to access information and support?
More than 77% of adults own a smartphone in US

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

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

Dashboard
• Summary of progress
• Badges earned, child behavior ratings, usage metrics

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
- User profile information
  - Family Forum interactions
- Summary of progress with learning modules
- Quick access to daily ratings, child behavior tracking, and usage metrics
Example: Reframing Module

- Educational text/audio
- Exercises to practice content
- Animations and videos
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
- Users share ideas, ask questions, get support
- Organized in sub-forums
- Moderated by trained peers
Evaluation of Design and Components

• Method
  • 7 focus groups were completed in 5 U.S. cities

• Recruitment
  • Provider referrals
  • Parent support groups
  • Online listservs and newsletters
Findings: Global Impressions

Overall Positive App Features/Aspects

- Ease of Access
- Guiding & Organizing
- Connection
- Share with Others
Findings: Systems Barriers

Limited Access to Services

Feeling Isolated

Lack of Knowledge & Need for Advocacy

Ease of Access

Connection

Connection

Share with Others
Findings: Individual Components

Positive Features of Individual Components

- Logo/Icon
- Learning Modules
- Library
- Family Forum
- Notebook
- Dashboard

Concerns and Considerations

- Who/What for?
- Wanting Answers Now vs. Learning Module Flow
- Privacy and Safety
What's Next?

**Years 1-2**
- **FMF Connect Development**
  - February 2018: Design Interface Programmed
  - March 2018: Family Forum Programmed

**Year 3**
- Feasibility Trial (n=30)
  - October 2018: Audiovisuals Programmed
  - August 2018: Educational Content Programmed
  - June 2018: Family Forum Programmed

**Years 4-5**
- RCT (n=120)
  - March 2019: Initial Feasibility Prototype Complete

**Focus Groups**

- **What's Next?**
  - 03/08/2019 CIFASD Plenary: Christie Petrenko, Cristiano Tapparello
  - 22
Questions

Comments

Feedback