

Family-Centered Tailoring of Pediatric Diabetes Self-Management Resources

June 19th, 2014
PCORI Regional Workshop

University of Wisconsin School of Medicine and Public Health
Medical College of Wisconsin

Outline for Today's Presentation

- Project overview
- Successful engagement of parent advisors
- Impact of advisors on study's outcome measures
- Successful engagement and impact of youth advisors
- Engaging stakeholders to optimize implementation
- Impact of external advisory board on implementation

Project Overview

- Long-term goal is to provide families with the best help for managing diabetes, ultimately improving blood sugar control and quality of life.
- 3-year study compares usual pediatric diabetes care to care enhanced by a family-centered self-management approach
 - *Care that respects the patients' wants, needs and preferences and solicits their input on the education and support they need to make decisions and participate in their own care*
 - A teenage patient identified the research question

Challenges in Diabetes Self-Management

- Half of the kids with type 1 diabetes struggle to achieve control
- Diabetes can negatively affect quality of life
- Families experience unique barriers to management
 - Staying motivated
 - Parent and child working together as a team
 - Having the knowledge and skills needed
- These barriers are related to control and quality of life

Existing Interventions Have Limited Uptake

- Evidence-based self-management resources exist
- Previous studies find families don't access these
 - Typical intervention is about 9 individual sessions over a period of 9 months
 - <30% agree to participate, even when paid \$200

Family-Centered Tailoring of Diabetes Self-Management Resources

Issue Limiting Access

No way to match to barriers

Family-Centered Approach

Tailored intervention uses 10 minute survey to identify barrier

Family-Centered Tailoring of Diabetes Self-Management Resources

Issue Limiting Access	Family-Centered Approach
No way to match to barriers	Tailored intervention uses 10 minute survey to identify barrier
Family feels alone and guilty	Tailored intervention is provided to groups of families with same barrier

Family-Centered Tailoring of Diabetes Self-Management Resources

Issue Limiting Access	Family-Centered Approach
No way to match to barriers	Tailored intervention uses 10 minute survey to identify barrier
Family feels alone and guilty	Tailored intervention is provided to groups of families with same barrier
Not enough available providers	Tailored intervention is provided in groups, serving 6-8 families

Family-Centered Tailoring of Diabetes Self-Management Resources

Issue Limiting Access	Family-Centered Approach
No way to match to barriers	Tailored intervention uses 10 minute survey to identify barrier
Family feels alone and guilty	Tailored intervention is provided to groups of families with same barrier
Not enough available providers	Tailored intervention is provided in groups, serving 6-8 families
Cannot miss more school or work days	Tailored intervention is delivered on same days as 4 clinic visits

Stakeholder Engagement in Preliminary Work

- Parent/youth surveys to identify self-management barriers
 - Parents/youths from JDRF identified comprehensive item pool
- Pilot study offered resources matched to two barriers (n=60)
 - Family teamwork
 - Diabetes knowledge and skills
- Those receiving intervention had 0.8% improvement in A1c
- ~70% consistently attended the group sessions

"I really like how we can all get together and talk about the problems we share."

Acknowledgements

- Community-Academic Partnerships core of the University of Wisconsin Institute for Clinical and Translational Research, funded through an NIH Clinical and Translational Science Award, grant number 1 UL1 RR025011
- UW Hilldale Research Scholars Program
- UW Shapiro Summer Research Program
- UW Department of Pediatrics Research and Development Funds
- UW Graduate School

Research Question

- Compared to usual care, can family-centered tailoring of diabetes self-management resources improve outcomes that matter to youth/parents?
- Outcome measures
 - A1c
 - Quality of life for the youth and parent
 - Youth/parent anxiety about having a low blood sugar

Participants

- 300 children who are 8-16 years of age and their parents
 - Receiving routine diabetes care at two large pediatric clinics in Wisconsin
 - 150 usual care (control)
 - 150 intervention
- Exclusions
 - Newly diagnosed (diabetes <12mo)
 - Non-English speaking
 - Families better served by intensive, one to one resource
 - Those without at least one self-management barrier

Anticipated Challenges

- Recruiting and retaining “hard to reach” populations
 - Rural families
 - Inner city families
- Implementing the intervention in two different clinics
 - Different patient populations
 - Different staffing and workflow
- Developing and evaluating the intervention to optimize future potential for dissemination to care systems broadly

Stakeholder Engagement



Overarching purpose is to ensure the study addresses questions that matter to families, the implementation is successful in real world clinics, and the study findings can be disseminated to healthcare broadly.

Outline for Today's Presentation

- Project overview
- Successful engagement of parent advisors
 - Betty Kaiser, PhD
- Impact of advisors on study's outcome measures
- Successful engagement and impact of youth advisors
- Engaging stakeholder to optimize implementation
- Impact of external advisory board on implementation



Wisconsin Network
for Research Support

WINRS



CARDS

COMMUNITY ADVISORS ON
RESEARCH DESIGN AND STRATEGIES

*Real-life feedback on research
and educational materials*

- Wisconsin Network for Research Support*
- Advice on plain-language research materials
- Experience recruiting, training lay advisory groups

Recruitment Planning for Advisory Boards

- Clarified role, responsibilities for board members
- Developed plain language invitation letter,
application

Training for Advisory Boards

- Focused and fun
- Strategies to build personal connections
- Meaningful activities designed for adult learners

Active Learning Strategies

- Self-assessments
- Brainstorming
- Dramatizations and role-play
- Case studies about privacy, confidentiality

Recommendations

- Develop timed agenda for training session
- Be prepared to adapt
- Evaluate training and debrief with project team

Outline for Today's Presentation

- Project overview
- Successful engagement of parent advisors
- Impact of advisors on study's outcome measures
 - Rosanna Fiallo-Sharer, MD
- Successful engagement and impact of youth advisors
- Engaging stakeholder to optimize implementation
- Impact of external advisory board on implementation

Parent Advisors Shaped Hypoglycemia Anxiety Survey

- Anxiety about low blood sugar matters
- Existing tools to measure this outcome are not sensitive enough
- Parent input has been instrumental in helping us refine the tool
 - What does the question mean to you?
 - Have we captured your anxiety fully, as you experience it in your life?
 - What else should we ask about?
 - Are there other ways that low blood sugar makes you anxious?

The Impact of Parent Feedback on the Hypoglycemia Anxiety Scale

Total items in original scale	19 items
Total items in new scale	20 items
Number of items deleted	4 items
Number of items added	5 items
Total % of items changed	100%

Impact of Parent Input--Example #1

- Part 1: Choose the answer that best describes how much you worry that your child might have a serious low blood sugar reaction in each situation described below:

<input type="checkbox"/> I don't worry at all	<input type="checkbox"/> I worry a little	<input type="checkbox"/> I worry quite a bit	<input type="checkbox"/> I worry too much
---	---	--	---

- Check the column that best describes the level of worry you usually have about your child having a serious low blood sugar reaction in situations like these:

None	A little	A lot	Too much
------	----------	-------	----------

Impact of Parent Input--Example #2

- “I give more carbohydrates (carbs) than my child’s doctor or nurse has recommended”
- I give more carbohydrates (carbs) than recommended

Impact of Parent Input--Example #3

- What is the lowest blood sugar at which you let your child go to bed without giving a snack?
- **On a typical day** what is the lowest blood sugar at which you let your child go to bed without giving a snack?

Parent Comments

- “I really like the idea of helping people that are so afraid of lows that it reduces their quality of living.”
- “The survey was very worthwhile, but I felt the time was way too rushed. The group could have given much more feedback.”
- “I really like seeing the potential research materials, and it was very helpful to have a researcher available to make the intent clearer.”

Outline for Today's Presentation

- Project overview
- Successful engagement of parent advisors
- Impact of advisors on study's outcome measures
- Successful engagement and impact of youth advisors
-Kathryn Murphy, PFL and Katie Glass, CCLS
- Engaging stakeholder to optimize implementation
- Impact of external advisory board on implementation

Engaging Children in Research

- What is Child Life?
- Creating a “kid friendly” environment and promoting positive group dynamics
- The importance of YAB and TAB
 - Two separate groups = one mission

ALL ABOUT ME



My first name is Allie

I like to be called Allie

I am 10 years old, and my birthday is 2/17

I live at home with Mom, Dad and Dustin

I have 0 sister(s) and 1 brother(s) and their names and ages are

Dustin, 9 years old

My pet at home is a Dog its name is George

I am in 11th grade and the name of my school is Edgewood High School

The subject I like most is Math

I am involved in these activities/clubs Swim team, ski racing and Track

My friends are Annie, Heather, Julie

Here are a few of my favorite things:

Music Type Pop TV Show Big Bang Theory

Book Hunger Games

Sport Swimming

Movie FROZEN

Food/Drink Popcorn

If I could meet one famous person it would be Big Bird

If I could travel anywhere, I would go France

My dreams for the future are to be a teacher

Before I go to bed I _____

These things help me fall asleep _____

Other things about me that I would like you to know I LOVE Animals



Engaging Children in Research

- Educating kids on the “ins and outs” of research
- Creating buy-in to understand role

GROUP RULES!

- * Wait to talk, til someone is finished
- * Be respectful to other's property
 ↓
 ↓ others
- * Take care of yourself
 * If you need help (low/or high blood sugar)
 Please ask for help.
- * Everybody Participates
- * Pay attention
- ~~Confidentiality~~
 what is said here, stays here.
- * Don't be disrespectful.

I pledge to follow the YAB
Group Rules:

Member

Member

Member

Member

Member

Member

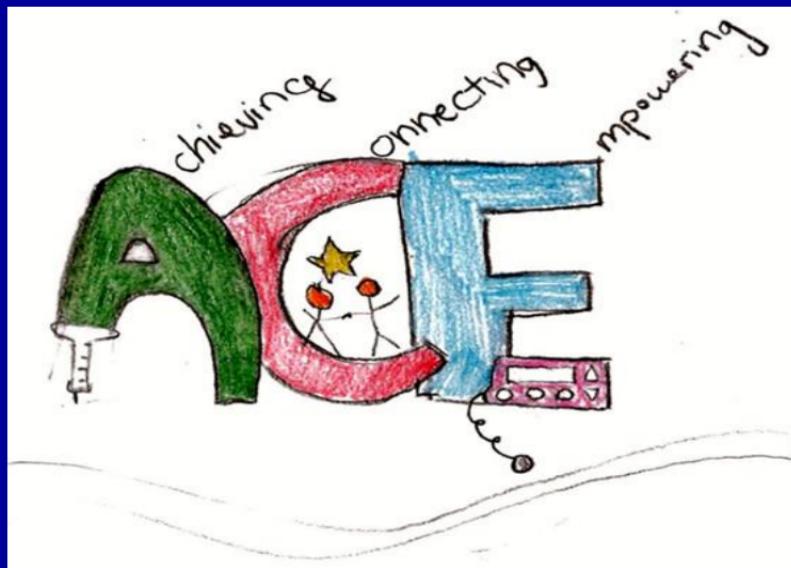
Member

Member

Member

Engaging Children in Research

- “Making is a difference is FUN!”



Youth Submission from Logo contest

Outline for Today's Presentation

- Project overview
- Successful engagement of parent advisors
- Impact of advisors on study's outcome measures
- Successful engagement and impact of youth advisors
- Engaging stakeholders to optimize implementation
 - Nancy Pandhi, MD, PhD
- Impact of external advisory board on implementation

Benefits of Individual Interviews

- Allows engagement at times & locations accessible for participants
- Opportunity to enhance knowledge through asking additional questions of future participants
- Allows for private and confidential conversations

Pre-Intervention Interviews with Parents and Clinical Staff Team

American Family Children's Hospital
(n=21)

- 10 Parents
- 11 Clinical Staff
 - Doctors
 - Nurses
 - Medical Assistants
 - Schedulers
 - Information Assistant

Children's Hospital of Wisconsin
(n=17)

- 7 Parents
- 12 Clinical Staff
 - Doctors/Nurse Practitioners
 - Nurses
 - Medical Assistant
 - Schedulers
 - Clinic Manager
 - Diabetes Educator
 - Social Worker

Two Approaches Used

- RE-AIM Framework from the dissemination and implementation literature
- Process flow mapping from industrial engineering

RE-AIM Pre-intervention Questions

Reach

- What are potential barriers & facilitators to patient/family participation in the study?

Effectiveness/Efficacy

- What beliefs do patients/families and staff have about the outcomes of the study?

Adoption

- How can we engage the staff throughout the study process?
- How do we develop organizational support?

RE-AIM

Implementation

- What are overall and/or site-specific issues that might influence implementation of the survey or group sessions?

Maintenance

- How might the effects of the intervention continue over time?

Example Questions - Reach

- What kinds of challenges do you think families might face when participating in the study?
- What kinds of things could we [the study] do to make it easier for families to participate?

Reach

Patient/family motivators for participation in study

Hard to find support group in local area

Opportunity to network with other families with diabetes

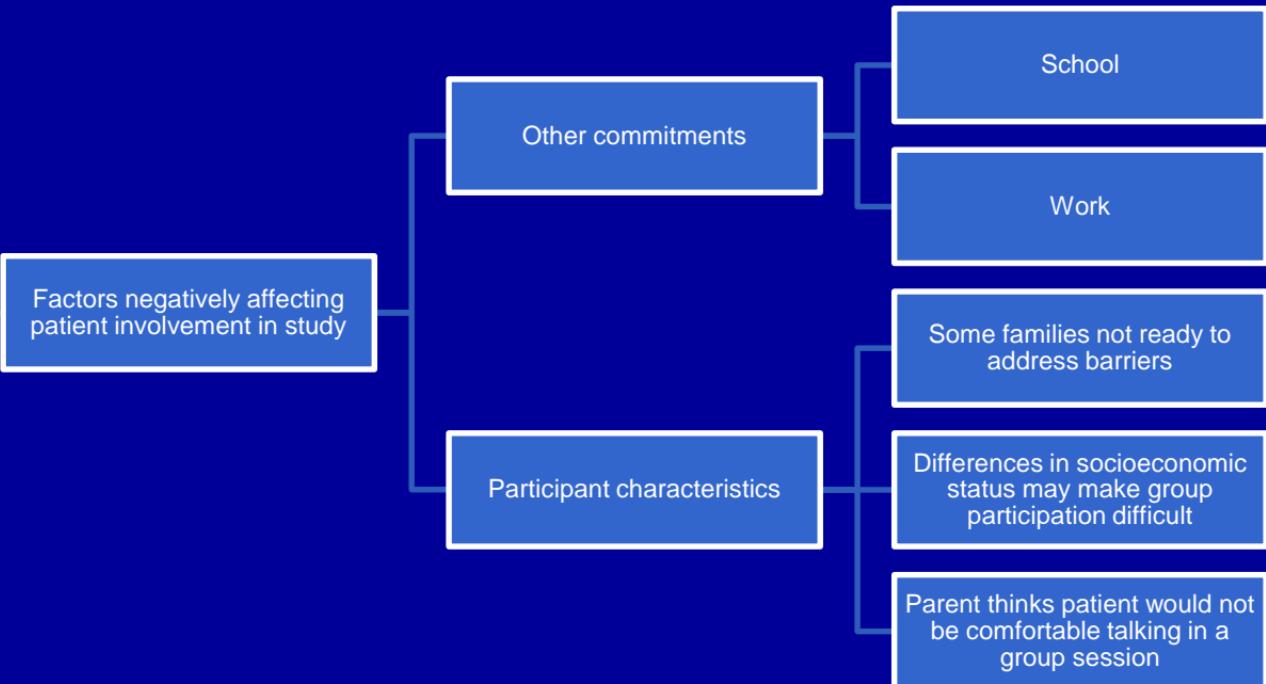
Opportunity to share knowledge with other patients/families

Provides time to discuss issues without children present

Opportunity for patient to receive education about diabetes from someone other than parent

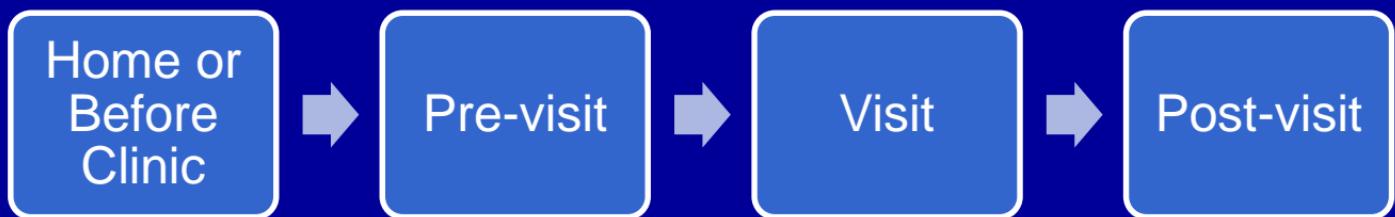
“So it would just be nice if, if he could begin to get an understanding and an education that came from somewhere other than me. So that he would understand the importance of it and actually talk to people who have, you know, long term dialysis...or you know, something that he wants to prevent.”

Reach



“She probably doesn’t want to talk in a group. That’s one of the reasons [she would not participate]. You know, they’re teenagers... they don’t like to share information if they can avoid it.”

Developing Further Understanding via Process Flow Mapping



Example Questions

- Walk me through what happens on the day of your visit?
- What challenges does your team typically face in working together to make clinic visits go smoothly?

Process Problems/Solutions Example – Home or Before Clinic

- Missing study sessions due to bad weather
 1. Have a protocol in place on what to do if study participants (control & intervention) cancel due to bad weather
 2. Provide patients/families with a phone number/way to contact research staff or group session leaders to let them know they will be late or not attending

Process Problems/Solutions Example – Post-visit

- Scheduling future clinic appointments and/or group sessions
 1. Have patients/families schedule their appointments and/or groups sessions for the entire year at the first visit
 2. Inform schedulers and study participants the blocks of times they should schedule their routine clinic visit

Adaptations Made After Interviews

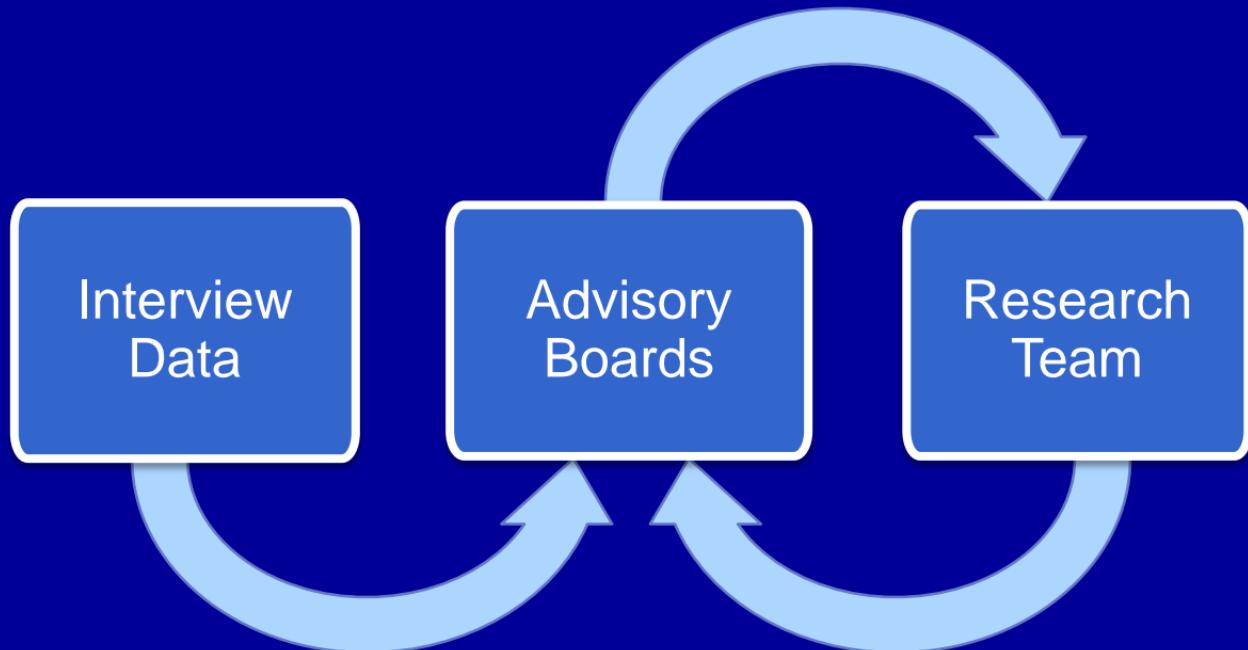
- Addressed **family barriers** to receipt of intervention
 - Bringing siblings along to visit
 - Forgetting to plan for extra time at visit
- Addressed **organizational barriers** to implementation and sustainability of intervention
 - Holding clinic appointments
 - Scheduling grids

Outline for Today's Presentation

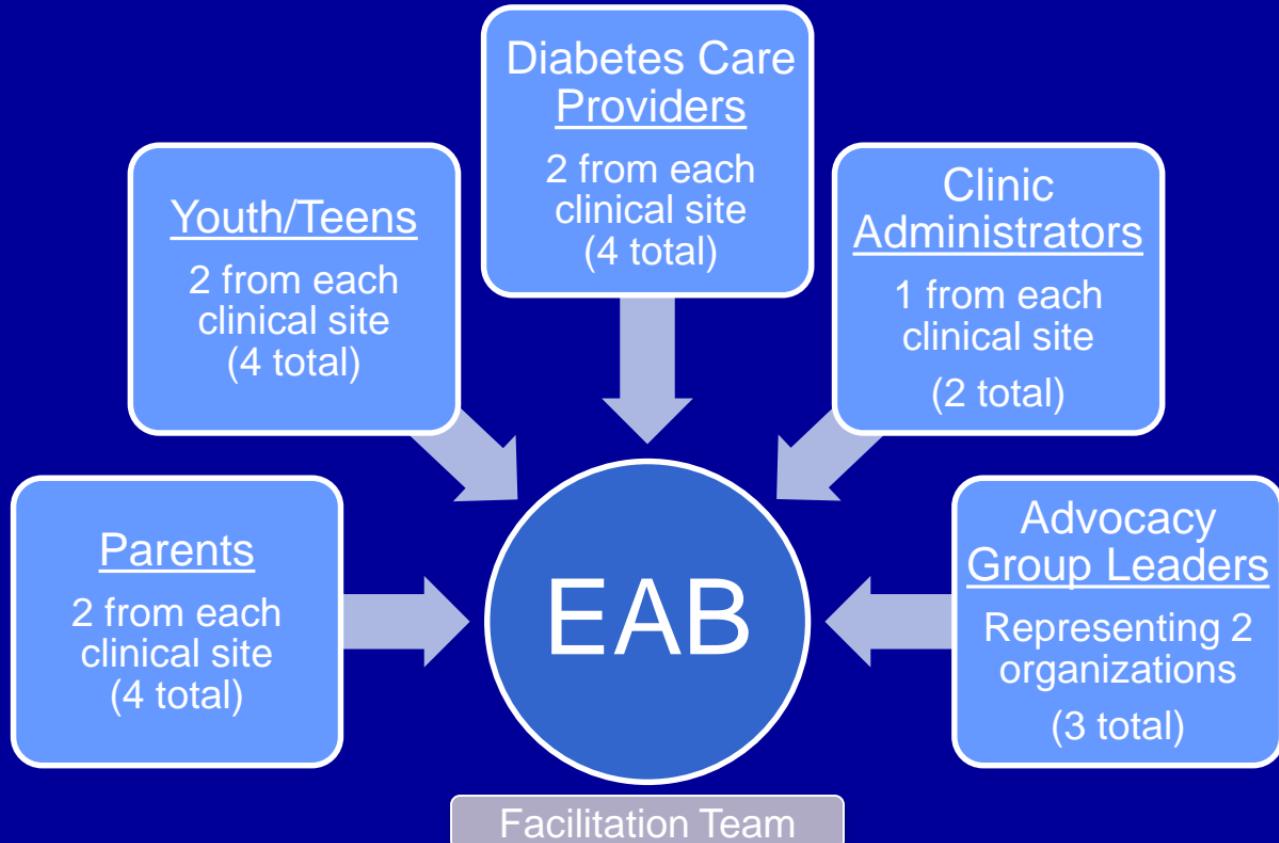
- Project overview
- Successful engagement of parent advisors
- Impact of advisors on study's outcome measures
- Successful engagement and impact of youth advisors
- Engaging stakeholder to optimize implementation
- Impact of external advisory board on implementation

Gwen Costa Jacobsohn, PhD

Iterative Feedback Process



External Advisory Board (EAB)



The Value of Multi-level Stakeholder Boards

- External Advisory Board Mission
 - Engage stakeholders with diverse roles and perspectives in meaningful dialogue
 - Collaborate to generate ideas, provide feedback, and address issues
- Why bring together different types of stakeholders?
 - Create connections between stakeholder groups
 - Engage in perspective-taking
 - Promote organizational buy-in, have champions for the project
 - Operationalize solutions

How Engagement Shapes the Research

MONDAY DIABETES CLINIC	
Provider 1 appointments	Provider 2 appointments
8:00 AM	
8:15 AM	8:15 AM
8:30 AM	
8:45 AM	8:45 AM
9:00 AM	
9:15 AM	9:15 AM
9:30 AM	
9:45 AM	9:45 AM
10:00 AM	
10:15 AM	10:15 AM
10:30 AM	
10:45 AM	10:45 AM
11:00 AM	
11:15 AM	11:15 AM
1:00 PM	1:00 PM
1:15 PM	
1:30 PM	1:30 PM
1:45 PM	
2:00 PM	2:00 PM
2:15 PM	

Identified potential issues in the timing of group sessions:

- Single parents
- Job scheduling constraints
 - e.g., hourly jobs, lack of schedule flexibility
- Travel time

Real-time Problem Solving

- Results
 - Willingness to make changes
 - Change provider schedules or available appointment times
 - Collaboratively-developed ideas for solutions
 - Limit to half-day
 - Commitment to making solutions work
 - “We are just going to get this done”

Summary

- In the initial 6 months of our project, youths, parents and other stakeholder groups have positively impacted the study design and conduct.
- Stakeholder and family engagement has helped guide us toward effective, feasible and sustainable ways of providing family-centered diabetes self-management resources.
- As challenges arise in the future, we look to our stakeholders and families to help develop and operationalize solutions.