

Meaningful Family Engagement

Promoting Equity In Care For Children & Youth With
Epilepsy In Rural & Underserved Areas Of Michigan

Presented at the Michigan Premier Public Health Conference
October 5, 2017



OBJECTIVES

- Understand the social, economic, and environmental conditions negatively impacting children and youth with epilepsy (CYE) living in rural and underserved areas.
- Gain new information about evidence-based/promising practices utilized to promote equity in care and epilepsy management for CYE living in rural and underserved areas.
- Recognize how meaningful family engagement can address inequities in access to quality health care.

DISCUSSION POINTS

- Project Overview
- Supporting Data
- Family Engagement Promising/Best Practices
- Successes and Challenges
- Questions and Answers

BACKGROUND

Three HRSA grant cycles:

- 2010-2013: Michigan Innovative Strategies in Serving Children & Youth with Epilepsy (CYE) → Telemedicine
- 2013-2016: Access & Awareness to Care for CYE → Telemedicine
- **2016-2019:** Michigan Strategic Approaches to Improving Access To Quality Care for CYE → **Beyond Telemedicine**

Implement quality improvement
practices, using a Learning
Collaborative model, to support medical
homes & comprehensive care
coordination: epilepsy action plans,
transition planning, telemedicine &
user-friendly technologies

Increase access to
quality health care for
CYE in Michigan

PARTNERS



American Academy of Pediatrics
Michigan Chapter



Beaumont Children's



PROJECT GOALS:

What does improved access to quality care for CYE look like?



**Coordinated Care in
a Patient-Centered
Medical Home**



**Transition
Infrastructure**



Specialty Care

STRATEGIES

QI Learning Collaborative

Webinars ♦ QI Projects ♦ PDSA Cycles
♦ Team Calls ♦ In-Person Meetings

Family Engagement

Parent/Youth Consultants ♦ Project Advisory Team ♦ QI-Leadership Team ♦ Outreach & Training ♦ Evaluation

Outreach & Education

Parent Mentor Trainings ♦ Care Coordination Trainings ♦ Providers ♦ CYE & Families ♦ LHDs ♦ Schools

Statewide Partnerships

Epilepsy Foundation of Michigan, Family Center, Beaumont Children's, Children's Hospital, DeVos Children's Hospital, UPHS: Marquette, MPHI, MI-AAP, U-M CHEAR, and targeted primary care providers from rural and underserved areas.

Marketing & Communication

Marketing Plan ♦ website ♦ workshops
♦ professional meetings

Innovative Technologies

Telemedicine ♦ teleconferences ♦ smart phone apps ♦ e-resources

Michigan Pediatric Epilepsy Telemedicine Sites

PRIMARY CARE CLINICS

Currently Offer Telemedicine

- ✘ Alcona Health Center – Alpena, Harbor Springs, Cheboygan
- ✘ Dickinson CHS Peds. Clinic – Iron Mountain
- ✘ Partners in Pediatrics – Saginaw

Previously Active with Telemedicine

- ◆ East Jordan Family Health Center
- ◆ Health Delivery, Inc. – Saginaw
- ◆ Baldwin Family Health Care
- ◆ Tawas/St. Joseph Pediatrics
- ◆ Thunder Bay Family Health Svcs.- Atlanta
- ◆ Forest Hills Pediatric Assoc. – Grand Rapids

Potential New Telemedicine Sites

- ✘ Holland Pediatric Associates – *re-activating*
- ✘ St. Clair Teen Health Center
- ✘ Sturgis Hospital
- ✘ UPHS clinic – Menominee
- ✘ DeVos specialty clinic – Traverse City



PEDIATRIC EPILEPSY SPECIALTY CLINICS

Currently Offering Telemedicine

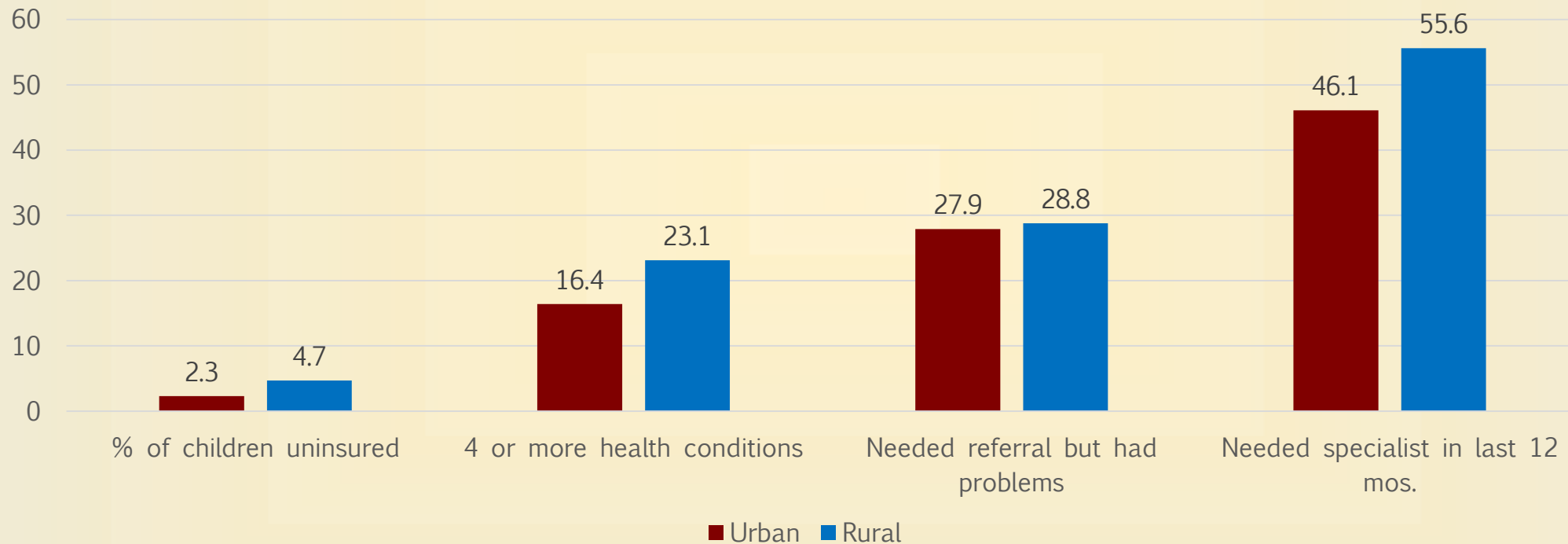
- CS Mott Children's Hospital
- Marquette General Hospital

Planning to Offer Telemedicine

- Beaumont Children's Hospital
- Children's Hospital of Michigan
- DeVos Children's Hospital

RURAL & URBAN DISPARITIES

Health Care Conditions & Access to Care in Michigan's Urban and Rural Areas



Sources:

1. National Survey of Children's Health. NSCH 2011/12. Data query from the Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health website: www.childhealthdata.org.
2. National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative. Data Resource Center for Child and Adolescent Health website: www.childhealthdata.org.

Identifying Gaps & Needs of Children & Youth With Epilepsy

PARENT SURVEY (2016)

- Administered by University of Michigan CHEAR Unit (Child Health Evaluation & Research)
- 22-question survey mailed to 3,334 parents of CSHCS enrollees with epilepsy diagnosis focused on:
 - Challenges accessing health care
 - Epilepsy action plans
 - Parent and family support
 - Transition
 - Additional supports needed from CSHCS
- 934 surveys returned (29% response rate)
- 1,000+ free text responses submitted

PARENT SURVEY FINDINGS

PROBLEMS GETTING EPILEPSY SPECIALIST CARE

63% TRAVEL more than 30 minutes to their child's specialist

56% Are interested in using TELEMEDICINE

"Due to travel time (4+ hours), it means extra money and time off work."



CARE COORDINATION

28% Don't have an Epilepsy ACTION PLAN

51% Don't have a MEDICAL HOME

"What is an action plan???? My child has had seizures for years, many Drs., and no one has talked to me about this?"

30% had at least one problem with specialist (long waits, transportation)

37% indicate their child is interacting directly with provider during visits (talking to provider, answering questions)

PARENT SURVEY FINDINGS (continued)

Parent Interest in Training

Transition to adulthood for children with epilepsy **39%**

Emotional health for CYE **35%**

CYE sibling workshop **23%**

Advocacy for CYE **21%**

Care coordination **20%**

Being a parent mentor **14%**

Best Practices



**Patient &
Family
Engagement**

Partnerships with Patients & Families: Recommendations & Promising Practices

- 1. Inform and convince** policymakers, administrators, health care providers, educators, and patients and family members of the importance and value of partnerships with patients and families.
- 2. Offer opportunities** for health care administrators, educators, and providers to learn practical strategies for implementing and sustaining patient- and family-centered care.
- 3. Employ patient and family leaders** in meaningful positions in the health care system.
- 4. Work with community groups** to educate consumers to expect partnerships in their own health care and meaningful roles in health care institutions and the health care system.
- 5. Enlist accrediting bodies** in developing standards related to partnerships with patients and families and patient- and family-centered care.
- 6. Enlist purchasers and payers** in expanding their definition of quality to include outcomes that reflect patient- and family-centered practices and to utilize such criteria in payment.

Source: Johnson, B., Abraham, M., Conway, J., Simmons, L. Edgman-Levitan, S., Sodomka, P., Schlucter, J., and Ford, D. Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System. Recommendations and Promising Practices. Institute for Patient- and Family-Centered Care, Bethesda. April 2008

Family Engagement Successes

- Parent Representatives on Learning Collaborative Clinic Teams
- Written “Parent Involvement Expectations” & reimbursement policies
- Parent sharing panels at statewide meetings/conferences
- Parent Consultant on staff
- Youth Consultant (in process)
- Family Engagement Consultant



Family Engagement: Parent Perspective



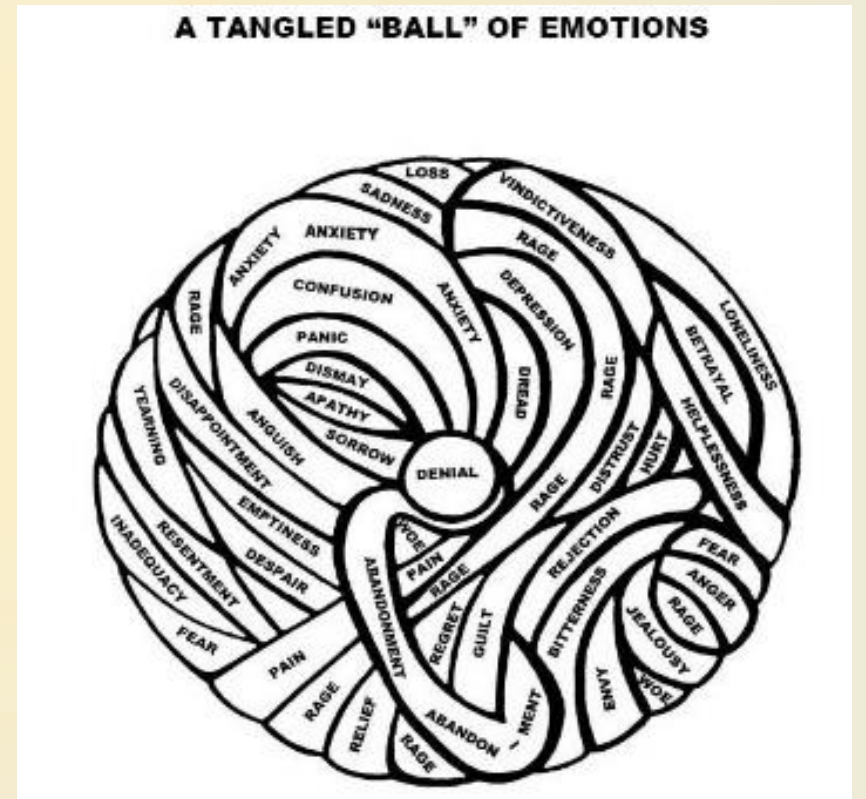
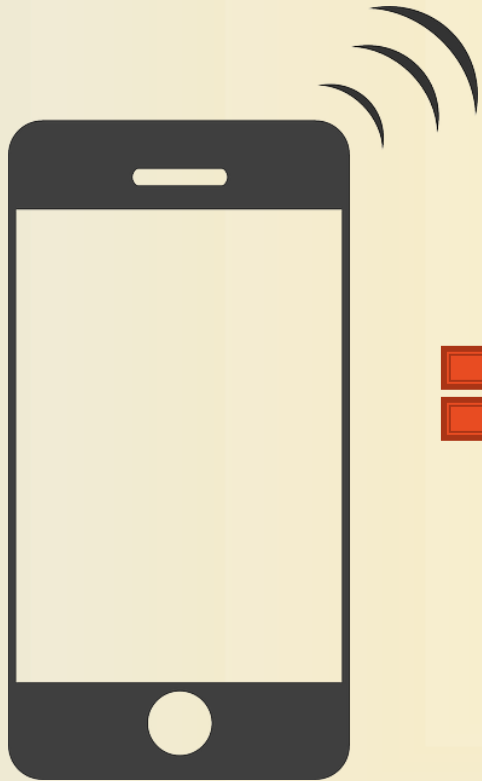
Special Delivery

* “Normal” Pregnancy *

- Zaharion “Toot”
- 14.5 hours of labor
- 8 pounds 5 ounces
 - 21 inches long
- PERFECT BUNDLE of JOY



September 2011



No matter how much I had prepared myself for this phone all...I still was NOT prepared!



*Family
Adjustments*

*Health
Insurance?*

Supports?



- **Epilepsy – 09/2011**

- **MEDS**
 - Low Bone Density
 - Side Effects
 - Etc
- ADHD
- Parasomnia
- Insomnia
- Night Terrors
- Sensory Processing Disorder
 - Occupational Therapy
- Behavior Issues
- Anemic
- Difficulties with Daily Living Skill
- Academic Problems
 - Difficulties reading, writing and math
 - Language Problems
 - Difficulties with Comprehension

- **Cortical Dysplasia – 12/2015**

- **Repeat**

Employment

- **10.2013 – Present:** Family Support Partner
 - **ASK Family Services (formally Parent to Parent (P2P) of SW MI)**
- **11.2015 – Present:** Parent Consultant - Michigan Pediatric Epilepsy Project
 - **Family Center for Michigan and Youth with Special Health Care Needs**
 - Children's Special Health Care Services
 - Michigan Department of Health and Human Services



Parent Consultant

Michigan Pediatric Epilepsy project



Parent Perspective

- Share personal stories about living with epilepsy
 - Local Health Department (LHD) Meeting
 - Provide feedback on the overall project
 - User Friendly “Seizure Tracking Apps”
 - Provide feedback on social approaches to increase and improve telemedicine awareness
 - Provide feedback and support other parents of CYE
- Parents Survey
 - Case Managers Conference
 - Q1 Leadership Team
 - Advisory Team
 - Face-to-Face Meeting for CYE Project
 - Parent Panel

Outreach Events: Engaging Families

- Michigan Council for Exceptional Children (MCEC)
- Michigan Transition Services Association
 - Transition is difficult
 - Epilepsy/Seizure Action Plan
- Epilepsy Foundation Michigan
 - Summer Stroll for Epilepsy
 - Talking to other parents
 - Sharing resources
 - Encourage networking with other families of CYE
 - Increase partnerships of families with CYE
 - Increase family-provider partnership in shared decision-making for all aspects of care for CYE
 - Family-Center Medical Home



■ Parent Mentor Training:

- Recruit other parents/caregivers
- Various locations across the state of Michigan
- 1 day Training = 5
 - Evidence based model adapted from the national Parent to Parent USA Organization



■ Other duties

- Create Parent Support Group Scholarship Application
- Review project materials
- Etc.

Staying Connected

Rubontay Buckner

ASK Family Services

Family Support Partner

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**Family Center for Children and Youth with
Special Health Care Needs**

Michigan Pediatric Epilepsy Parent
Consultant



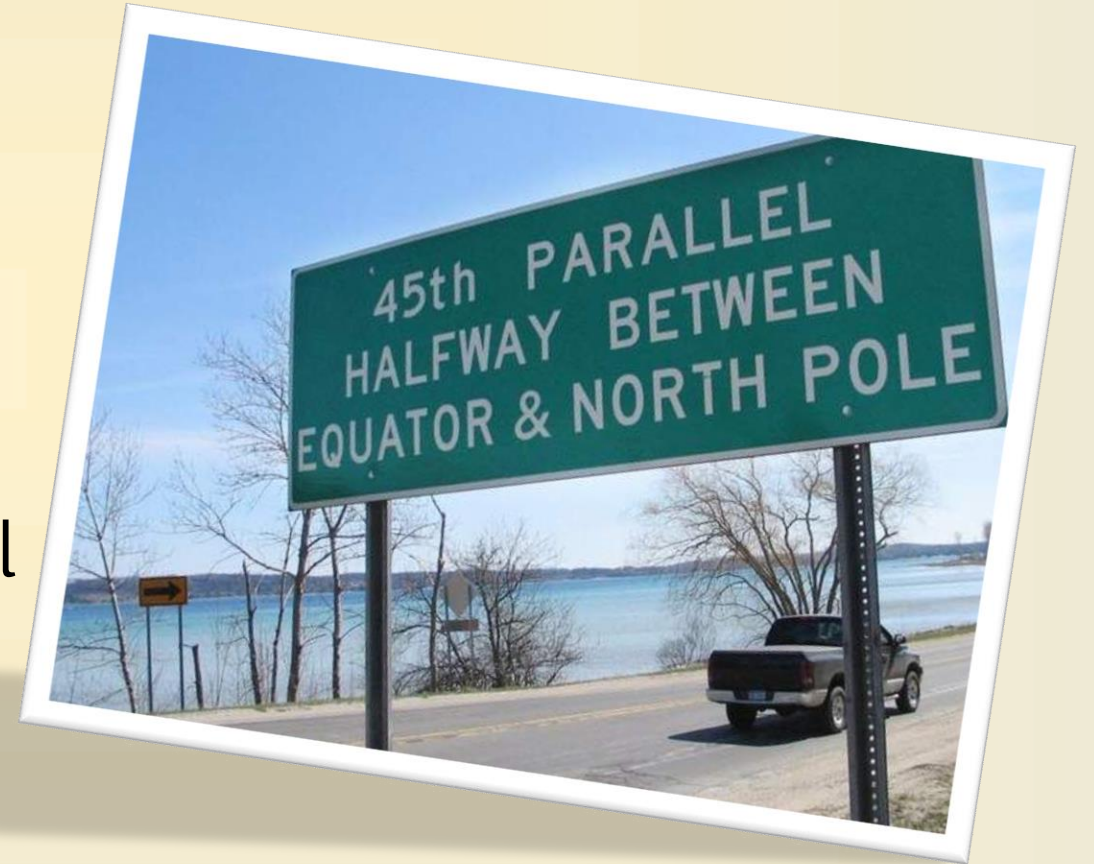
Keeping Up w/ Toot



keepingupwithtoot@gmail.com

Challenges to Successfully Engaging Families

- Common understanding of “meaningful family engagement”
- Funding to compensate family partners
- Time commitment/geography
- Establishing a mutually beneficial partnership
- Others?



QUESTIONS?

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THANK YOU