



**Novel Interventions in  
Children's Healthcare (NICH):  
Engaging Patients and Families**

# Bending the Curve in Medicaid

**Problem: 4% of patients utilize 50% of medical resources**

# Triple Aim

**Improving health**  
**Improving care**  
**Reducing costs**

**The only way to meet triple aim is by involving/engaging patients and their families/caregivers**

# NICH Families

- **Marginalized by the healthcare system**
- **Children's health moves down on priority list because of families being heaped under a mound of psychosocial challenges**

# NICH Family Profile

- **46% - Single parent household**
- **48% - Unemployment / employment insecurity**
- **11% - Out of home, with extended family**
- **46% - Not in school**
- **38% - Housing insecurity / homelessness**
- **59% - Family isolated; no support**
- **24% - Youth involved in substance abuse**
- **76% - Youth w psych/behavior problems**
- **27% - Family has DHS involvement**

# Patient and Family Engagement



# Where the Rubber Meets the Road

- **Establish rapport & get “buy in”**
- **Understand context & challenges**
- **Clarify expectations**
- **Determine next steps**
- **Pay attention to and reinforce “small wins”**
- **Serve as care ambassador**
- **Assist in re-engaging with care**
- **Support disease management & problem solving**
- **Titrate services**



# NICH Intervention

- **24/7 therapeutic support**
- **BFST – family-based problem solving**
- **Pragmatic & systematic behavioral intervention**
- **Case Management and Care Coordination across contexts**
  - **Medical**
  - **Social services**
  - **Community mental health**
  - **School**
- **School consultation**
- **Employment, social and life skills coaching**

**Care Coordination**

Attend Clinic Appoint  
Ensure Transportation to Clinic  
Medical Supplies  
Liaison Between Medical  
Team and Family  
Care Ambassador

**Behavioral Family  
Systems Therapy**

Problem Solving  
Communication Skills  
Training  
Family Roles and  
Structure  
Address Family Conflict  
Establish Proper  
Supervision

**CF  
Diabetes  
ESRD  
Pain  
Cancer**

**Case Management**

Working with School  
Help with Job  
Interface with DHS  
Resources for the Family

# Delivery of Care

- **Inpatient**
- **Clinic**
- **Tele-health**
  - **Skype (1-2x/wk)**
  - **Text (daily)**
  - **Phone (daily)**
- **Home visits (weekly)**
- **Care coordination (daily)**
- **School visits (as necessary)**

# NICH Diagnoses

- **2 Cystic Fibrosis**
- **4 Chronic Pain**
- **16 Diabetes**
- **2 Cancer**
- **4 Recurrent Abdominal Pain**
- **3 End Stage Renal Disease**
- **3 Pulm/Card**
- **1 Eating Disorder**

# Case Example: 15 year old type 1 diabetic

- Disengaged completely from care providers
- Very skeptical
- Marginalized
- Poor experiences in ED, hospital and with PCPs
- Changed providers 7 times
- 30 ED visits in 3 months

# Engagement

- First contact
- Getting “their” story
- Respect
- Language

# Case Example: 15 year old Cystic Fibrosis

- **Cystic Fibrosis**
- **Chronic productive cough**
- **Frequent visits to ED for coughing, shortness of breath and chest pain**
- **Admitted twice last year for pulmonary exacerbations**
- **Lung function at baseline normal**
- **Recent chest-CT showed mild airway thickening**

# Complicating Medical & Psychosocial Factors

- **Chronic constipation**
- **CF related liver disease**
- **History of malnutrition and g-tube**
- **History of ADHD and oppositional defiant disorder**
- **Lack of financial resources**
- **School absenteeism**



# Complicating Medical & Psychosocial Factors

- **Complex treatment regimen:**
  - Enzymes with every meal
  - CF Vitamins and Miralax daily
  - G-tube feeds nightly
  - Omeprazole and Metoclopramide daily
  - Airway clearance therapy twice daily
  - Inhaled antibiotic twice daily
  - Inhaled mucolytic daily
  - Inhaled hypertonic saline daily
  - Flonase daily
  - Flovent twice daily
  - Azithromycin Monday-Wednesday-Friday

# Complicating Medical & Psychosocial Factors

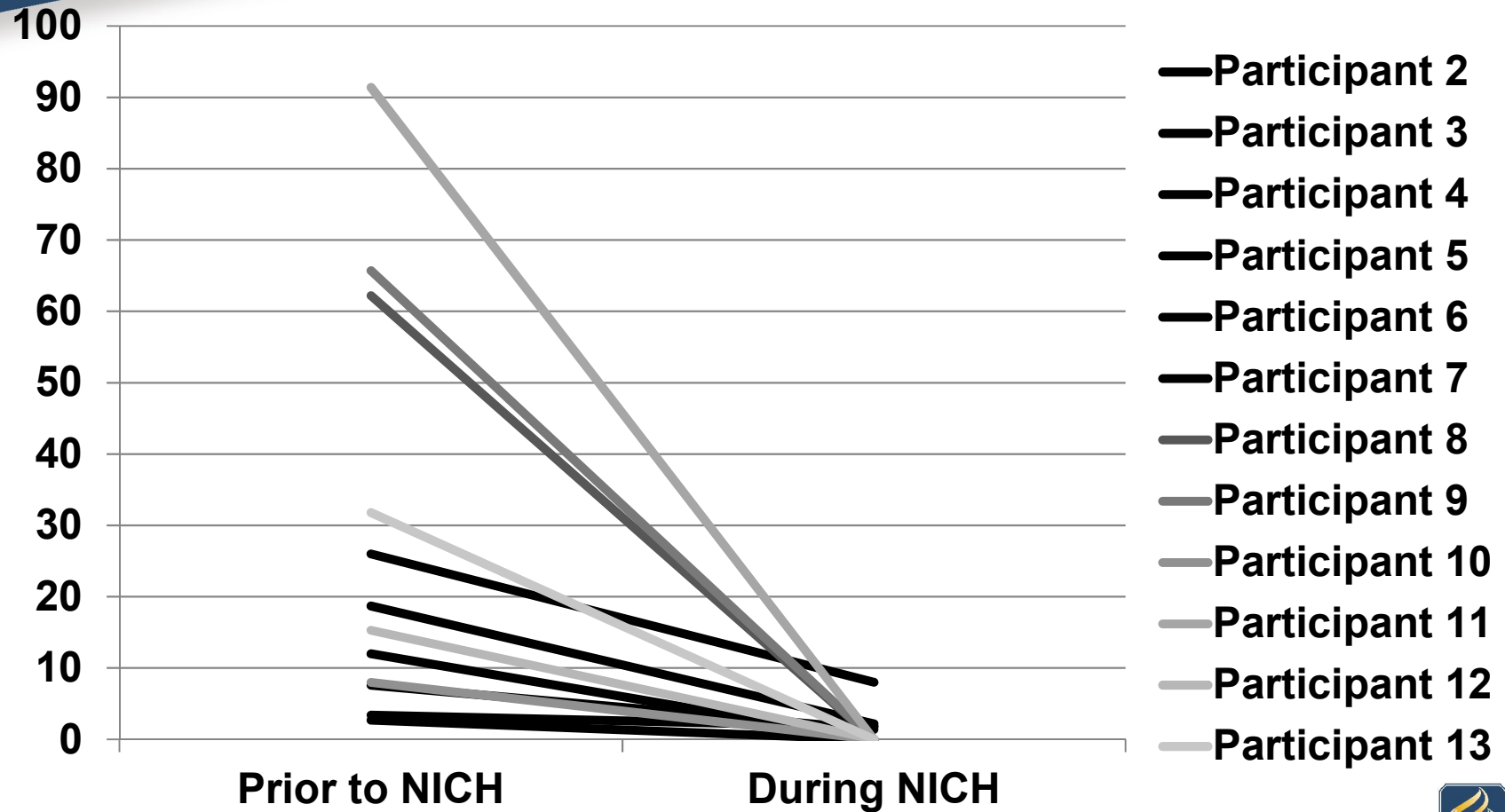
- **Excessive use of ED**
- **Housing insecurity, food insecurity, MH issues**
- **Out of school for 1 yr**
- **Terminated from community MH agency**
- **Non-compliance with prescribed medical regiment**
- **Police called to home 8x/2 months**
- **DV relationship with boyfriend**



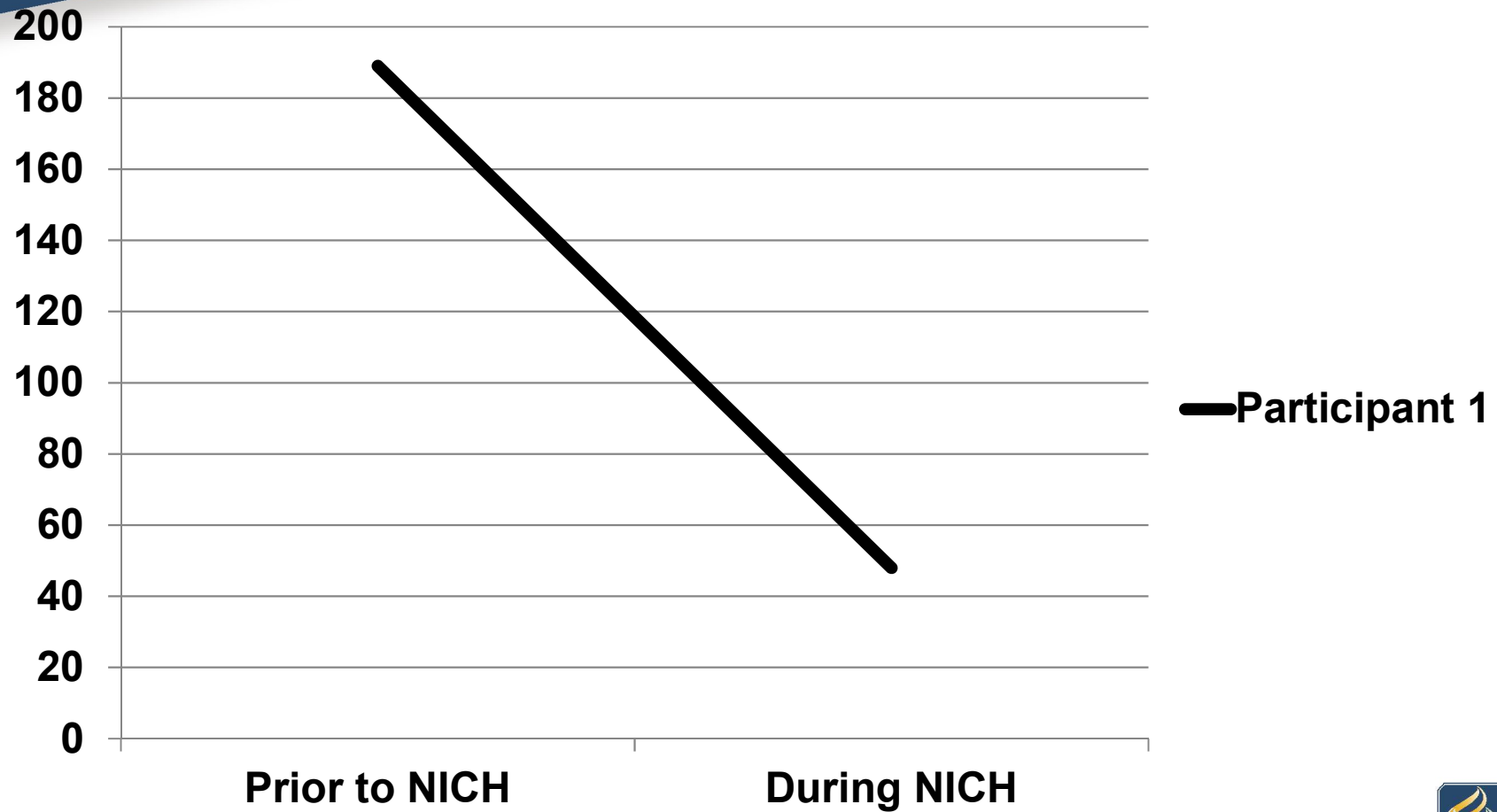
# NICH Intervention

- **DHS report**
- **Crisis intervention plan**
  - contact NICH staff to assess need for accessing ED
  - Discussion with NICH staff → support call to CF staff → clinic visit in place of ED visit
  - 0 ED visits since execution of plan
- **Behavior contracting targeting adherence**
  - Texted photos taking medication and doing nebulizer treatments
- **School support and consultation**
- **Targeted parenting skills, problem-solving, communication and family structure**
- **Re-engagement in appropriate social activities**
- **Intervened in DV relationship with boyfriend**
- **Development of coping strategies**
- **Re-engagement with community MH services**

# Days Hospitalized/Year



# Days Hospitalized/Year



# Comments and Questions

