Novel Interventions in Children’s Healthcare (NICH): Engaging Patients and Families
Problem: 4% of patients utilize 50% of medical resources
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
• 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
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 Appointment
- 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 regimen
- 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

Prior to NICH

During NICH

Participant 2
Participant 3
Participant 4
Participant 5
Participant 6
Participant 7
Participant 8
Participant 9
Participant 10
Participant 11
Participant 12
Participant 13
Days Hospitalized/Year

Prior to NICH | During NICH
---|---
0 | 0
20 | 180
40 | 160
60 | 140
80 | 120
100 | 100
120 | 80
140 | 60
160 | 40
180 | 20
200 | 0

Participant 1
Comments and Questions