Paediatric Complex Care Coordination – a Pilot Project

Taming of the Queue
March 24, 2011
Pilot Project Team

**Shaundra Ridha**
Director Corporate Patient Services, CHEO-Pilot Administrative Lead

**Allison Budge**
Manager Client Services, Paediatric Program, Champlain Community Care Access Center (CCAC)

**John Graf**
Family Member, CHEO Family Forum

**Nimet Karim**
Family Member, CHEO Family Forum

**Sheila Bauer**
Acting Director Children’s Hospital of Eastern Ontario (CHEO)

**Dr. Nathalie Major-Cook**
Paediatric Medicine, CHEO-Pilot Most Responsible Physician (MRP)

**Katherine Moreau PhD (c)**
CHEO Research Institute (RI)

**Nimet Karim**
Family Member, CHEO Family Forum

**Ann Marcotte**
Program Administrator, Life Span, Ottawa Children’s Treatment Centre (OCTC)

**Julie Milks**
Manager, Ambulatory Care, CHEO

**Katherine Moreau PhD (c)**
CHEO Research Institute (RI)

**Shaundra Ridha**
Director Corporate Patient Services, CHEO-Pilot Administrative Lead

**Chantal Krantz RN, MScN**
Project Manager, CHEO

**Natasha Tatartcheff-Quesnel**
Manager, Coordinated Access (CA)
Presentation Overview

- Background
- Problem
- Program Objectives and Desired Outcomes
- Model of Care
- Key Elements
- Program Evaluation
- Facilitators and Challenges
- Replicating
Children’s Hospital of Eastern Ontario (CHEO) Family Forum advises the CHEO Board of Trustees on quality of care.


CHEO families believe that one coordinated point of access would greatly enhance the continuum of care.
The Literature Says

- Advances in medical technology mean more children are living longer with chronic illnesses.

- Between 13 and 18% of children/youth live with a chronic condition [i]

- These children account for 80% of the healthcare costs attributed to children overall. [i]

- Children with chronic health issues are 3x more likely to require intensive care hospitalization [ii],[iii]

- 32% of these admissions are potentially preventable [ii],[iii]

- 64% can be attributed to system deficiencies such as care coordination, medical errors and errors in care as a result of the complexities of care. [ii],[iii]

---


The Reality in Champlain LHIN is 2009

- System is not child/youth and family focused
- Organizations were working in silos
- Complex, medically fragile children are orphans to system
- No mechanisms to share information across system
  - Fragmented care [i] [ii] [iii]
  - Frequent and prolonged hospitalization [ii]
  - Risk of medical errors and duplication [iii] [iv]
  - Parental stress and burnout [v]

Child - Genetic and GI issues
TPN, Central line dependant GJ-tube

CHEO
- MDU - Dressing change
- ICU
- Blood work
- GI
- Orthopedics
- ENT
- GI Dietitian
- Sibling
- OCTC
- MDU - Dressing change
- Blood work
- GI
- Orthopedics
- ENT
- GI Dietitian
- Sibling

Parents
- Palliative care team
- School
- OT
- Physio
- Teaching Aid
- Nursing support

CCAC-Home
- Equipment
- Funding
- Nurse daily Paramed
- Health Care Aid at night

OCTC
- Community Pharmacy
- TPN
- Service Coordination

CHEO-Pharmacy
Program Objectives

- Provide a family-centered approach
- Facilitate communication and collaboration among care providers
- Coordinate the child/youth and families needs across the system (home, community and hospital services)
- Relieve the burden of care coordination on families and improve health status
Desired Outcomes

- Improved overall satisfaction
- Increased family involvement
- Improved system navigation
- Reduction of duplication
- Improved health status
  - reduced ED visits
  - reduced inpatient Length of Stay (LOS)
  - reduced events of hospitalization
  - Improved family health
The Pilot Framework
Patient Engagement

- Involve families at all levels and stages
  - Defining the problem
  - Concept development
  - Planning phase
  - Implementation
  - Evaluation
Care Coordination Model

Informed, Satisfied Patient and Family

Prepared Proactive Care Teams

Community

Children's Hospital of Eastern Ontario (CHEO)

Coordinated Access

CCAC
OCTC

ADVISORY COMMITTEE

FAMILY FOCUSED TEAM

Shared EHR

MRP = most responsible physician
EHR = electronic health record

Desired Outcomes

Productive Interactions

Adapted from The Chronic Care Model, Wagner, E.H., 1998.
Key Elements to the Pilot

- Most Responsible Physician (MRP) and Nurse Care Coordinator housed at CHEO.
- “Family Coordinator” to help navigate the system
- Family Focused Teams to support families and will help address priority issues.
- 1.5 hour clinic intake assessment and 30 minute f/u appointments as needed
- Single Point of Care Document (SPOC)
- Medical Road Maps
- The Family Care Coordination binder storing all participant medical information in a single location-belongs to family
- Child and Adolescent Needs and Strength (CANS) Assessment
- Advisory Committee with community partners to help advise and work through system barriers.
The Family Participants
**Characteristics n = 21**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologically impaired</td>
<td>19 (90.4%)</td>
</tr>
<tr>
<td>Number of medical conditions per child</td>
<td>10 (6-16)</td>
</tr>
<tr>
<td>Number of medications per child</td>
<td>5 (1-12)</td>
</tr>
<tr>
<td>Technology dependent:</td>
<td>15 (71%)</td>
</tr>
<tr>
<td>Enteral feed (n = 11)</td>
<td></td>
</tr>
<tr>
<td>Tracheostomy (n = 4)</td>
<td></td>
</tr>
<tr>
<td>VP shunt (n = 1)</td>
<td></td>
</tr>
<tr>
<td>Ventilation (n = 3)</td>
<td></td>
</tr>
<tr>
<td>Marital status; intact family</td>
<td>15 (71%) *</td>
</tr>
<tr>
<td>Community physician: Pediatrians</td>
<td>17 (81%)</td>
</tr>
<tr>
<td>Family MD</td>
<td>4 (19%)</td>
</tr>
<tr>
<td>Vaccinations up to date</td>
<td>9 (42.8%)</td>
</tr>
</tbody>
</table>

* Estimated from project documents
Program Evaluation
## Program Evaluation Framework

<table>
<thead>
<tr>
<th>Evaluation Issues/Questions</th>
<th>Indicators</th>
<th>Data Source</th>
<th>Data Collection Methods</th>
<th>Bases for Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implementation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Are the activities of the Pediatric Complex Care Coordination Project being implemented as intended? | - Project implementation plans  
- # of implementation challenges  
- # of services/activities being implemented | - Project documents  
- Project working group | - Document analysis  
- Focus group | - Project logic model |

| Accessibility                |            |             |                         |                      |
| Who is using the services of the Pediatric Complex Care Coordination Project? (demographics & characteristics) | - Demographic trends  
- Participant’s functioning, risk behaviors  
- Family/caregiver’s needs and strengths | - Health records  
- Project participants | - Child and adolescent needs and strengths (CANS)  
- Document analysis (demographic data) | - Inclusion and exclusion criteria  
- Other programs |
| What factors prompt families to participate in the Pediatric Complex Care Coordination Pilot Project? | - Participant attitudes and opinions | - Project participants | - Questionnaire survey (Open-ended question) | - Published literature  
- Other programs  
- Documented factors at baseline |
Baseline Data

What factors prompt families to participate?

improve

wellbeing

reduce

support

care

advocacy

health

communication

stress

continuity
Is there a reduction of hospitalizations & emergency room use?

What we do know...

Baseline Participant Group N = 25

<table>
<thead>
<tr>
<th>Item</th>
<th>Median (Min-Max)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of ED visits (24 months prior)</td>
<td>4 (0-14)</td>
<td>5.5 (4.7)</td>
</tr>
<tr>
<td>Number of ED visits (12 months prior)</td>
<td>2 (0-9)</td>
<td>2.8 (2.8)</td>
</tr>
<tr>
<td>Number of hospitalizations (24 months prior)</td>
<td>2 (0-12)</td>
<td>3.3 (3.5)</td>
</tr>
<tr>
<td>Number of hospitalizations (12 months prior)</td>
<td>1 (0-7)</td>
<td>1.9 (2.2)</td>
</tr>
<tr>
<td>Number of inpatient days (24 months prior)</td>
<td>11 (0-443)</td>
<td>46.9 (96.4)</td>
</tr>
<tr>
<td>Number of inpatient days (12 months prior)</td>
<td>3 (0-182)</td>
<td>23.2 (40.3)</td>
</tr>
</tbody>
</table>
## Health Status

What impact do the services have on children and their families?

Too early to tell...

Baseline Impact on Family Questionnaire (N = 20)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time is lost from work because of hospital appointments</td>
<td>17 (85%)</td>
</tr>
<tr>
<td>Our family gives up things because of my child’s condition</td>
<td>16 (80%)</td>
</tr>
<tr>
<td>Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable</td>
<td>14 (70%)</td>
</tr>
<tr>
<td>I am cutting down on the hours I work to care for my child</td>
<td>13 (65%)</td>
</tr>
</tbody>
</table>
The Literature Says

- Access to information reduces duplication, medical error and risk to child [i]

- Decreased stress for families: Significant improvement in perceived parental Health Related Quality of Life (HRQOL) noted at 12 months associated with improved mental health [ii]

- Improved health status of the child:
  - 55% reduction in ED visits one year into their project. [iii]
  - Sick Kids showed no decrease in ER use after one year but a decrease in hospital days from 43 to 15 [ii]
  - greater than 50% reduction in hospital days in a 3 year study [i]

Facilitators and Challenges
Facilitators

- Strong leadership and support from the CEO
- Top priority for all organizations involved
- Solid partnership with CHEO Family Forum
- Commitment to a Family Centered Model within the organization
- Collaborative partners dedicated to the cause
- Buy-in/support with front line staff both in hospital and the community
- Dedicated Physician (MRP)
- Supportive family participants
Challenges

- Communication with large multi disciplinary teams
- Lack of shared electronic system
- Changing practices
- Lack of standardized pediatric tools
- Funding to secure a program and research
- Randomizing participants and control/waitlist
- Expanding for an integrated approach
- Lack mechanism to track time to coordinate care.
- Transition to adult care
How Do You Replicate?

- Feedback from your frequent flyers
- Parent/caregiver representation at all levels
- Have a clear definition and project scope
- Create flow maps and adapt to reality
- Build your case, evaluate outcomes
- Measure cost savings, impact on health use and satisfaction to secure funding
- Ensure strong support and stakeholder involvement
- Develop a plan to ensure sustainability
- Build capacity
Acknowledgments

A special thanks to CCAC, OCTC, CA, CHEO, the RI and families for the tremendous collaboration and dedicated group effort!