Connecting Families: Development and Implementation of a Parent Mentoring Program

Nationwide Children’s Hospital
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Objectives

• Understand the benefits of a parent mentoring program

• Identify the steps involved in developing a disease-specific parent mentoring program
Background

- Opportunity to develop parent project idea
- When my son was diagnosed:
  - How I felt
  - What we wish we had
  - What we hear from other parent
  - What was missing
- How could this really help other parents?
- Share experiences
Developing the Idea

• Pitching of the idea
• Parent Driven
• NCH’s value of partnership with parents
• Plan for project, goal set, other ideas
• Mentoring a top priority for parents
Next Steps

- Create training guide for onboarding
- Monthly meeting with GI team
- Tracking and reporting of results
- Determine need for additional parent mentors
Previous Attempts

• Support Group
  – Difficult to sustain

• Informal connections
  – Inconsistent
  – Many limitations
Literature Review

• Parent to Parent support programs are an accepted part of the health care delivery system in chronic disease (AAP 1997)

• Qualitative research using parent mentors for children with diabetes (STEP): 3 types of support identified. Informational, affirmation, and emotional

• Anecdotal reports of benefits in children with special needs and of different ethnic backgrounds
Benefits of Parent Mentoring

- Experiential knowledge
- Normalization
- Emotional support
- Provide credible resources
- Mentors also benefited by feeling empowered, personal gratification and acknowledgment of their expertise
Initial Steps

• Evaluate how this concept would work within the GI department
• Evaluate how this concept fits into the hospital vision
• Consistent method for training mentors
Initial Steps: Within GI

- Wanted to make sure we could offer to all patients with IBD
- Multiple providers that all see patients with IBD
- Presented at department business meeting
Initial Steps: Hospital

- Identify key contacts within the hospital
  - Clinical Services and Care Coordination
  - Chief Nursing Officer
  - Legal services
  - Volunteer services
  - Other clinical departments
Consistent training

• Role responsibilities
• Training manual
• Onboarding process for new mentors
• Defined the implementation process
Hospital Resources

- CNO requested meeting to assess feasibility of centralized department
- Many departments represented
- Volunteer services support
- Allowed for hospital wide dissemination
IBD Mentor Program Today

• 9 mentors
• Offer mentors at new diagnosis, admissions, and starting a biologic
• 170 connections to date
Hospital-Wide Program

• Nearly 400 matches
• Over 40 different match reasons
• 8 different languages
• Parents, grandparents, young adult patients
• Remote program
Continual Growth

• Presentations
• Departmental relationships
• Specialty area contacts
• Mentor appreciation
• Relationship with mentors and mentees
Beyond Match Facilitation

• Electronic surveys
• E-mails to mentors and mentees
• Occasional follow-up phone calls
• Specialty area contacts
How do mentors and mentees connect?

- 47% Phone
- 33% Face-to-Face
- 7% Email
- 13% Combination
How often do mentors contact their mentees?

- 12% 1-3 times
- 24% 4-9 times
- 9% 10 or more times
- 55% Not at all

60% of mentees do not initiate contact with their mentors.
Mentees: How well did the match meet your support needs?

- 31% Very well
- 38% Extremely well
- 23% Slightly well
- 8% Not at all

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When your child needs a hospital, everything matters.
Use of Comments

- “I have only spoken with my mentor once and we had a nice conversation. I texted her after that one call but have not heard back, but I know she is very busy and I am too. I will reach out to her again. :-)

- “Mentor's daughter is on a different path than my daughter so we couldn't discuss some of the social issues I wanted.”
How likely are you to refer the program to other families?

- Not Likely: 43%
- Slightly Likely: 13%
- Moderately Likely: 2%
- Very Likely: 4%
- Extremely Likely: 38%
Mentor Feedback

“There is remarkable hope and strength gained from developing a sense of connection and community with someone whose trials may be similar to your own.”
Mentee Feedback

“When I first found out my daughter’s [diagnosis], I felt ashamed…..like I did something wrong. I never shared these feelings with anyone until [my mentor] told me her family’s story and she freely explained that she felt those same feelings.”
Thank you for attending

• Presentations:
  www.childrenshospitals.org

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