

# Development and Implementation of a Parent Navigation program in the NICU

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# Objectives

- Discuss the history of the parent navigation programs at Children's National Health System
- Describe the development and implementation of a peer support program for families after NICU discharge
- Discuss lessons learned during the process



# Children's National- Serving DC's children for 150 years

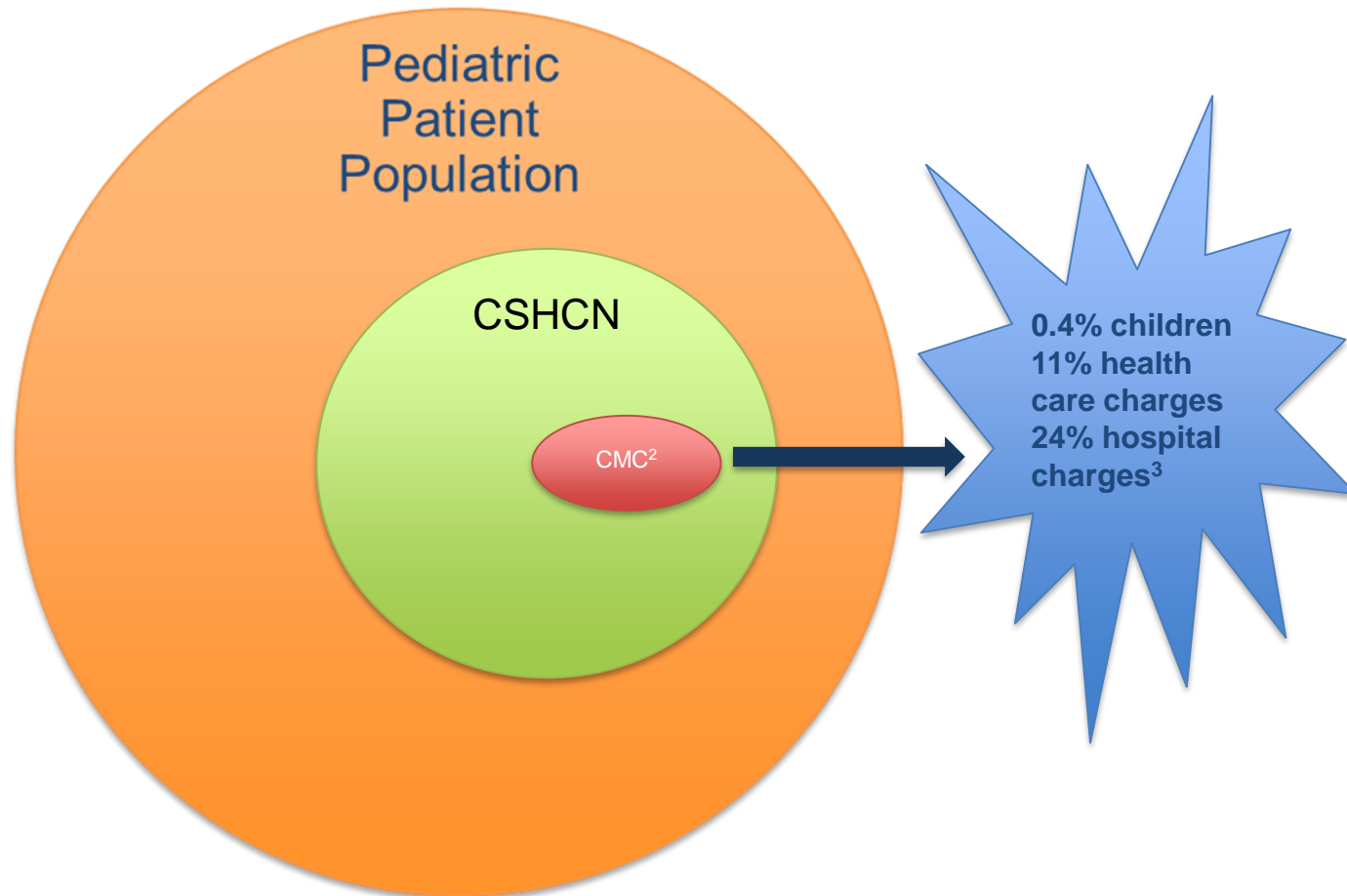


# History of Parent Navigation at Children's National

- Program established in 2008
- Based on the Pediatric Practice Enhancement Project of the Rhode Island Parent Information Network.<sup>1</sup>
- Funded by grant support
  - DC Department of Health, Community Health Administration
  - MD Department of Health and Mental Hygiene, Office of Genetics and People with Special Health Care Needs
- Parents of children with special health care needs (CSHCN) employed by the hospital to provide peer support to other families of CSHCN
- Available to families of CSHCN receiving primary care and complex care services at Children's National

<sup>1</sup>Rhode Island Parent Information Network.  
<http://www.ripin.org/about.html>

# Parent Navigators serve a medically complex patient population

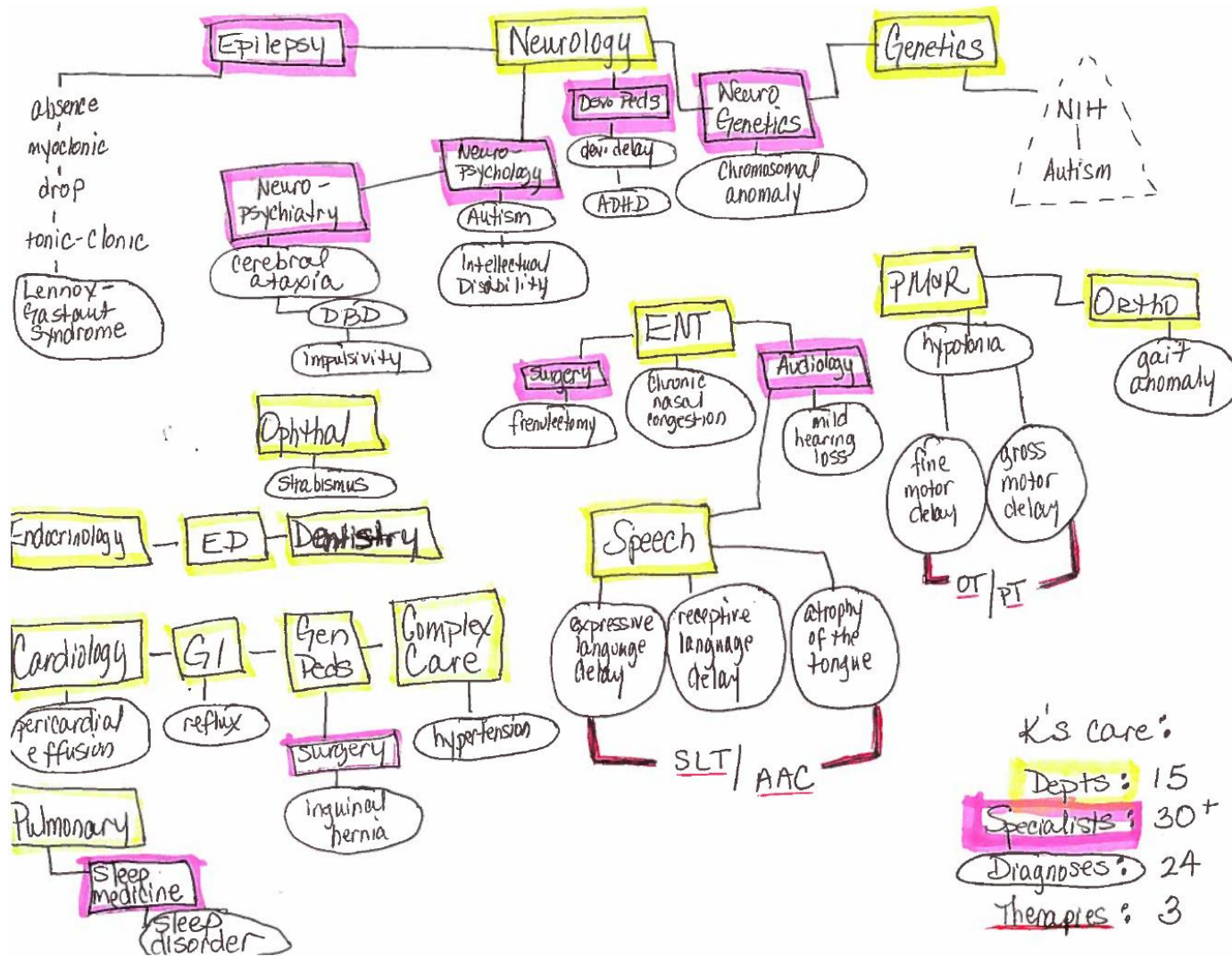


<sup>2</sup>Cohen, E., et al. (2011) Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*, 127(3), 529–538

<sup>3</sup>Neff JM, Sharp BL, Popalisky J, Fitzgibbon T. Using medical billing data to evaluate chronically ill children over time. *J Ambul Care Manage*. 2006;29(4):283-290.



# K's Care Map



# What do Parent Navigators do?

- **Mentorship**
  - Peer to peer support
  - Advocacy
- **Resources**
  - Housing
  - Education
  - Social Security application
  - Daycare assistance
  - Legal Services
- **Navigation**
  - Healthcare system
  - Community resources
  - Appointments





# Benefits of Parent Navigation

- Advantages of integrating PNs into the hospital system, medical home
  - Involvement on hospital committees
  - The voice of the parent is always heard
  - PNs involved in discharge process
- Parents offered peer support, feel less isolated
- Parents have access to community resources
- Parents feel empowered to advocate for their children





# Navigating the way home from the NICU

- About 400,000 US newborns require neonatal intensive care unit (NICU) care for prematurity, congenital anomalies, or complex medical conditions each year<sup>4</sup>
- Increased risk of long-term disability, cerebral palsy, deafness, blindness, and developmental delays <sup>5,6</sup>
- Parents of these infants report increased anxiety and stress during and after the NICU stay. <sup>7-8</sup>
- Some evidence that peer support/buddy programs improve patient satisfaction and decrease stress, anxiety, and depression for families of infants who had been in the NICU. <sup>9,10</sup>

<sup>4</sup>Martin JA, et al. Births: Final data for 2012. Natl Vital Stat Rep 2013; <sup>5</sup> Aylward GP, et al. The Journal of Pediatrics 1989; <sup>6</sup> McCormick MC. Pediatrics 1997; <sup>7</sup> Feeley N, et al. Applied Nursing Research : ANR 2011; <sup>8</sup> Lefkowitz DS, et al. Journal of Clinical Psychology in Medical Settings 2010; <sup>9</sup> Roman LA, et al. Research in Nursing & Health 1995;

<sup>10</sup> Willis V. Advances in Neonatal Care 2008.



# Would Parent Navigation be beneficial to parents leaving the NICU?

- Collaboration between General Pediatrics and the NICU
- PCORI proposal funded fall 2014, GPS project began January 2015
  - Enrolled 300 families of babies in the NICU who are approaching discharge
  - Randomized families to receive either a parent navigator for 12 months (intervention group) or a care notebook upon discharge (comparison group)
  - Obtained baseline, 1-week, 1-, 3-, 6-, and 12-month data on caregiver self-efficacy, stress, anxiety, and depression; infant healthcare utilization and immunization status





Giving Parents Support

- Focus groups of all stakeholders
- Development of a NICU parent navigator curriculum
- Hire and train NICU-specific parent navigators
- Integrate PNs into the NICU environment and into the discharge process



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# Care Notebook

GPS (Giving Parents Support):  
Parent Navigation After NICU Discharge

Introduction

About  
My Child

Dynamic  
Care Team

Care and  
Access Plans

Medical  
History

Medications

Insurance

Emergency

Resources

# Parent Navigation Training Curriculum

## Program Goals

1. Perform the duties and responsibilities of a parent navigator within a multidisciplinary team, including family, clinical staff, research team, and community providers.
2. Assess and recognize a family's emotional, financial, and social needs as they care for their NICU graduates to provide them with support and appropriate resources.
3. Employ resources and personal experience to empower families to advocate for their child within the healthcare system and community .



# Parent Navigation Training Curriculum

- **Identified topics relevant to the PN role**
  - HIPPA
  - PCORI-understanding the organization and the GPS project
  - NICU
  - Resources-internal and external
  - Boundaries
  - Communication skills
  - Needs Assessment/Intake
  - Cultural Sensitivity/Empathy
  - Advocacy
  - Clinical Documentation
  - Research Documentation
  - Bereavement
  - Conflict Resolution
- **Learning Objectives created for each topic**
- **Mapped each topic and its learning objective to one or more of the program goals**



# Parent Navigator Recruitment

- Unique skill set required
- No professional certification
- High school diploma +/- college education
- Bring their experience to the job but not to each patient encounter
- Ability to maintain good boundaries
- Three full time Parent Navigators were hired
- Each was at least one year past their NICU admission to allow for easy integration and better development of professional boundaries of PN.





# NICU Collaboration

- Engage NICU staff...beyond focus groups
  - Social Workers were involved in hiring
  - Talked about PN at staff meetings and with staff individually
  - Sending emails, flyers and a staff breakfast
  - Events and communication were strategically planned to reach staff on all shifts.
  - Frequent reinforcement
  - Full time research coordinator visible in the NICU
- Educate the PNs about NICU culture
  - PN attended rounds as part of training
  - Whole team was introduced to the NICU staff (walk around with meet and greet)
- Clear role definition



# Barriers to NICU-Parent Navigation implementation and ongoing success

- Not enough qualified candidates
- Some NICU parents have only recently been discharged, may need time to reflect on their experience, and may not be ready to be a peer mentor
- Securing ongoing funding after project is done
- Need to show Return On Investment (ROI)
- Clear role definition with members of the care team- both inpatient and outpatient



# Preliminary Results

## CESD-10 Scores at Baseline

Depression Symptoms	N(%)
None-Mild, score <10	162 (55)
Score $\geq 10$	135(45)

45% of caregivers at baseline have CESD scores above the clinical cutoff for depression

# Impact of research

- Development of a hospital wide interdisciplinary task force on perinatal mental health
- Systematic depression screening in the NICU
- Dedicated NICU Parent Navigator hired

# Current NICU Parent Navigator Program

- 1 FT PN since 2018
- Referrals from NICU care team, ideally >2 weeks before discharge referral time is 2 weeks or more before discharge.
- NICU PN meets family with care notebook, introduces program
- NICU PN rounds with team at least 2x/week while admitted

# Post Discharge NICU PN support

- PN calls family within 3 days of discharge
- Family followed weekly for 3 months after discharge and then monthly for first 6 months
- Attends subspecialty appointments with families, visits if admitted for an inpatient stay
- NICU PN and Complex Care PN will do handoff at 6 months if patient is being seen in Complex Care

# Next steps

- NICU PN program working to build relationships with community primary care providers
- Assessing impact of inpatient and post discharge parental support



# Building and sustaining a Parent Navigator Program

- Decide the type of support program for your population
  - Inpatient versus outpatient (or both)
  - Proactive versus reactive
  - If NICU based, consider how you will involve the primary care provider
- Identify and secure continued funding
- Clear role and job description, standardize parent navigation services within the institution
- Maintaining professional boundaries
- Overcoming communication barriers
  - Ineffective language interpretation
  - Literacy levels
  - Cultural differences
- Employer flexibility
- Ongoing training opportunities, certification possibilities



# Lessons Learned

- In order to maintain professional boundaries, parents of NICU graduates need to have adequate time to process their personal experiences prior to being hired as navigators.
- Optimizing communication with parents





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Thank you for your attention.