



Sala Institute for Child and Family Centered Care

# Families as Partners in a Co-Designed Family Stress Screening/Response System

Ron-Li Liaw, MD, Director, Center for Child and Family Resilience, Sala Institute for Child and Family Centered Care  
Beth Silber, MPA, Family Consultant, Sala Institute for Child and Family Centered Care

March 21, 2017

# Disclosures

- None of the speakers have anything to disclose.

# Who We Are

- **Ron-Li Liaw, MD**, Director, Center for Child and Family Resilience, Sala Institute for Child and Family Centered Care & Child Psychiatry Consultation Liaison Service
- **Beth Silber, MPA**, Family Consultant, Sala Institute for Child and Family Centered Care & Co-Chair, Family Advisory Council

# Learning Objectives

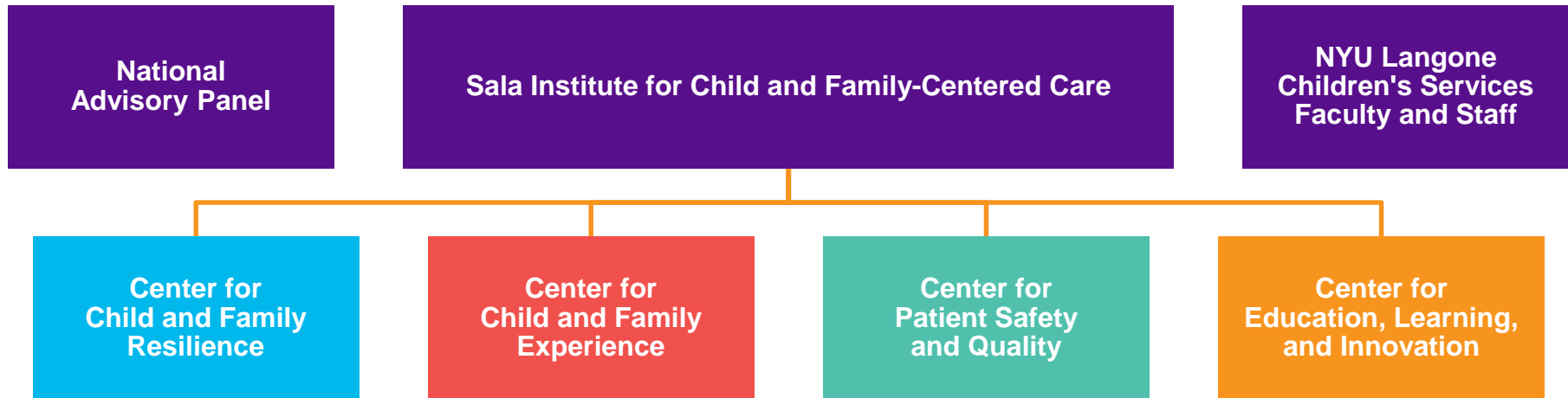
- 1) Develop strategies for integrating families as partners in designing, implementing, and evaluating quality improvement initiatives
- 2) Understand key elements and challenges in creating an interdisciplinary, effective, sustainable family stress screening/response system

# Transforming Care at Hassenfeld Children's Hospital



# An Innovative Model to Advance Patient and Family Engagement in Care, Safety, Quality, Research and Education

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# How The Work Gets Done: The Magic Of The Connection



# Center for Child and Family Resilience





# Center for Child and Family Resilience Strategic Goals

- Enhance and develop programs to provide **coping, comfort, and resilience support** for patients, families, and staff
- Develop and refine a comprehensive measurement strategy to assess the **effectiveness and impact** of resiliency programs

# Hospitalization & Stress

## PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

### Can Hospitalization Precipitate Toxic Stress?

Anita N. Shah, DO,<sup>a</sup> Karen E. Jerardi, MD, MEd,<sup>a</sup> Katherine A. Auger, MD, MSc,<sup>a</sup> Andrew F. B

Published online April 1, 2016

During morning rounds, I introduced myself to the parent of a patient with bronchiolitis. As trainees, we are taught the medical management of bronchiolitis and how to set families' expectations for the course of illness. However, we are not taught how to help

that trigger positive stress provide the opportunity "to observe, learn, and practice healthy, adaptive responses."<sup>2</sup> Alternatively, events that result in "extreme, frequent, or extended activation of the stress response," without adequate buffering,<sup>3</sup> are toxic,



Brief increases in heart rate, mild elevations in stress hormone levels.

Serious, temporary stress responses, buffered by supportive relationships.

Prolonged activation of stress response systems in the absence of protective relationships.

<http://developingchild.harvard.edu/science/key-concepts/toxic-stress/>

# AAP Policy Statement

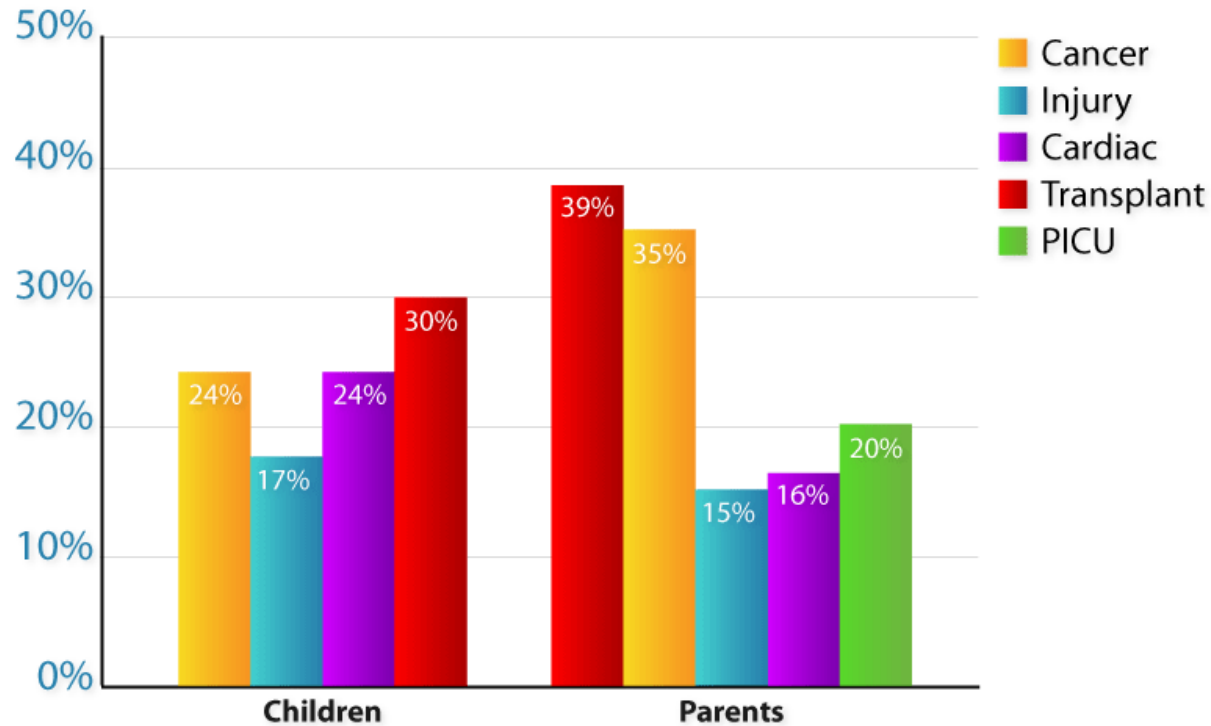
## Early Childhood Adversity & Toxic Stress

- Events that trigger **POSITIVE** and **TOLERABLE** stress may elevate the body's physiologic response system,
  - **SOCIAL SUPPORTS** buffer and preventing harm
- Events that result in extreme, frequent, or extended activation of the stress response, without adequate buffering, are **TOXIC**

**“Relationships lie at the roots of resilience.”**

- Suniya Luthar, PhD

## Percent of children & parents with significant traumatic stress symptoms after medical events



Prevalence of significant traumatic stress:

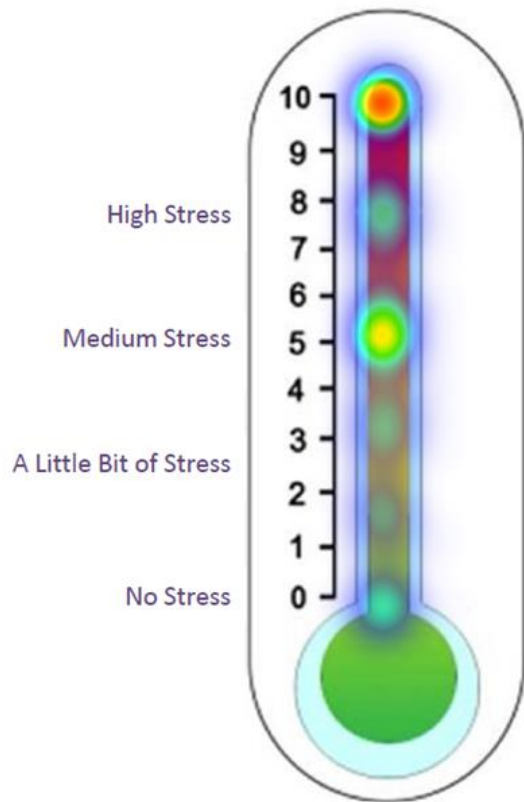
- 20% of injured children
- 12% of ill children
- **21-32%** of children in the PICU

Summary of research findings from The Children's Hospital of Philadelphia.

Summarized from peer-reviewed research studies, 1999-2009.

*Note: Traumatic stress levels in children in pediatric intensive care has not yet been well-documented.*

# PICU Family Stress Quality Improvement Project



- Using both an **improvement science** and **patient and family partnership** framework, our aim was to:
- Test, implement and sustain the use of
  - A co-designed **family stress screening tool**
  - An individualized yet standardized **response protocol**

# Quality Improvement Team

**Team Leader:** Ron-Li Liaw

**Nurse Managers:** Lea Devins & Tiffany Folks

**Medical Director:** Yasir Al-Qaqaa

**Resource Nurse:** Mary Rose

**Nursing Champions:** Lauren Selikoff, Terri Yarri, Caitlin Coit, Lauren Arrigoni & Kelsey Hanrahan

**Unit Clerk:** Guerline Dalrymple

**Family Advisors:** Jennifer Daly & Erik Ward

**Pediatric Social Work:** Lindsey Drewry, Dara Weiss, Debbie Dore & Erin Lauinger

**Child Life:** Jami Barretta & Megan Walsh

**Integrative Health:** Amy Eberhardt

**Chaplaincy:** Matthew Dimick

**Pediatrics Chief Resident:** Denis Chan

**Child Psych:** Yamalis Diaz & Becky Lois

**Nursing Education:** Kathy Linhart

**Project Manager:** Jeanne Cho



# Key Driver Diagram: Screening for Family Stress in the PICU Interventions

## Global Aim

To enhance emotional support for families and prevent crisis

## SMART Aim

*Increase the % of PICU families who are screened for stress during PICU stays from the current rate of 0% to 90% by June 30, 2016.*

Population: Families with PICU stays  $\geq 24$  hours

## Key Drivers

PICU staff well-trained & comfortable in using the ST & response protocol

Staff (PICU & support services) engagement & buy-in

Reliable process for administering ST

Adequate staffing to administer the ST

Open, bidirectional communication with diverse families

Generalizable response protocol  
•Time-efficient, value added  
•Ability to tailor for family's unique needs & situation

Stress management & resiliency support for PICU staff

Design & implement ST tool for assessing family stress (1)  
•Train staff to use the ST tool – just in time & simulation  
•Create scripting & orientation materials  
•Embed ST screening in PICU work flows (2)

Design & implement staff engagement campaign (1)  
• Orientation & unit awareness of impact of stress  
• Monthly stress reduction hours/events & incentives  
• Resiliency / wellness support programs

Design & test family stress response protocol (1)  
• Train staff on response protocol & roles  
• Embed response protocol in PICU work flows (2)  
• EPIC smart phrase & #PICUCares email (2)

Integrate ST tools within EPIC (2)  
• Design ST mHealth app, flowsheet & communication systems

ST staffing back-up  
• Unit clerk ST completion log & audits (2)  
• Task assistance offered by charge nurse & other disciplines trained to complete ST w/ families (1)

Engage FAC, senior family advisors, and family communication experts to create optimal approach for diverse families (2)

Create mirrored family-facing materials (1)  
• Bedside ST & resource list (welcome book)  
• Family-facing response protocol & stress management resources

### Key

Gray shaded box = completed intervention

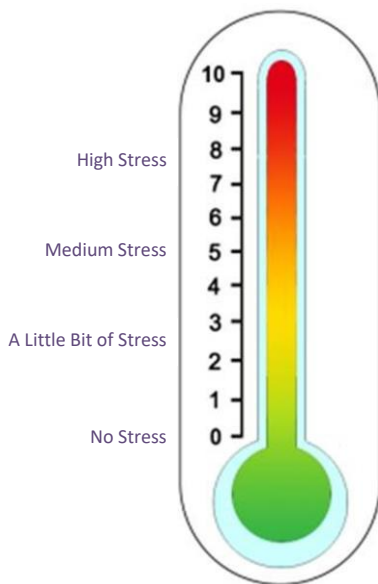
Purple shaded box = what we're working on right now

# Co-Designed Family Stress Thermometer

## How are you doing? (Caregivers)

When your child is in the hospital, it is natural for parents to feel stressed. If you are stressed, we want to support you.

On the thermometer below, please circle the number from 0 to 10 that best matches your stress level over the past 24 hours.



## High Stress

### Medium Stress

## A Little Bit of Stress

No Stress

Caregiver #1: \_\_\_\_\_

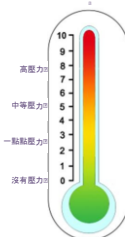
Caregiver #2: \_\_\_\_\_

### What Would Be the Most Helpful To You Right Now?

**您現在感覺如何？（看護者）** [How Are You Doing? (Caregivers)]

當您的小孩住院，身為父母當然會感到壓力。如果您的心理有壓力，我們希望能夠幫助您。

請在底下的溫度計，圈選一個0到10的數字，表示最符合您過去24小時的壓力程度。



造成您感到有壓力的原因為何？

### [What Is Causing Your Stress?]

(請在底下空白處告訴我們) 因



NYU Langone  
MEDICAL CENTER

كيف حالكم؟ (مقدمو الرعاية)  
[How Are You Doing? (Caregivers)]

على ميزان الحرارة الموجود أثناء جرحي وضع دائرة حول العدد من 0 إلى 10 والذي يطلق بشكل أفضل مستوى الضعف النفسي لديك في خلال الساعات الـ 24 الماضية.



ما الذي يسبب الضغط النفسي لك؟

### [What Is Causing Your Stress?]

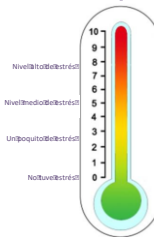
(أرجى تكرار في المساحة المخصصة أدناه)



¿Cómo se sienten? ¿Cuidadores? ||  
[How are you doing? Caregivers?]

Cuando el hijo está en el hospital, es natural que los padres se sientan estresados. Si  
está estresado, queremos apoyarlo.

En la siguiente thermometer, marque con un círculo el número de veces que mejor  
describe su nivel de estrés en los últimos 24 horas.



### ¿Qué le causa estrés?

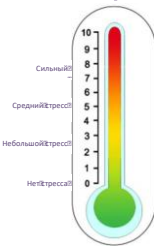
[What Is Causing Your Stress?]

¿Cuántos dígitos tiene el siguiente espacio?



Как вы себя чувствуете? (Лица, осуществляющие уход)  
(How Are You Doing? (Caregivers))

На рисунке видно, что в трудные моменты испытывает стресс 10 из 10, которое чуть выше, чем в среднем по уровню вашего стресса в последние 4 часа.



Что вызывает ваш стресс?

### What Is Causing Your Stress?

Изражение (2.10) называется **интегралом Лапласа** и обозначается



Instructions: After completing the Stress Thermometer with the patient's parent/caregiver, mark the responses you completed in the check boxes below. Please see the back of this sheet for the Response Log. If you have any questions about the response protocol, please reach out to Lea, Caitlin, or Kelsey.

Place Patient Label Here

Date & Time: \_\_\_\_\_

Staff Name: \_\_\_\_\_

Time to Complete (min): \_\_\_\_\_

Caregiver #1 Stress Score: \_\_\_\_\_

Caregiver #2 Stress Score: \_\_\_\_\_

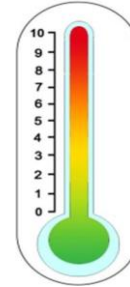
## Stress Thermometer: Response Protocol

Stress Thermometer Score

5 or higher

or

Staff Perceived Family Stress



If you are concerned about a safety issue, CUS with the PICU Nurse Leader and Attending

I am CONCERNED!

I am UNCOMFORTABLE!

This is a SAFETY ISSUE!

"Stop the Line"



### HUDDLE

Nursing Leader & Attending

Huddles are ad hoc sessions to review and modify the established plans to ensure all team members are on the same page and adjustments are made as needed. Keep them brief!

Did you address concerns about:

- ☐ Medical condition
- ☐ Care plan
- ☐ Communication
- ☐ Coordination
- ☐ Comfort

Did you schedule a family meeting?



### ADD SUPPORT

Hospital & Community

Referrals: Mon-Fri, 9am-5pm

- ☐ Social Work (212) 263-5018
- ☐ Child Life (212) 263-5585
- ☐ Chaplaincy (212) 263-5903
- ☐ (917) 240-7243
- ☐ Integ Health (212) 263-5767
- ☐ EPIC Consult

Nights & weekends, call page operator at 212-263-7300

Did you send a PICU Care email update?



### PERSONALIZED CARE

What would be most helpful right now?

Any other interventions used?

See the Response/ Re-assessment Log on the back of this sheet















## #PICUCares (email alias)

- PICU Nursing & Physician Leadership
- Nursing Champions
- Social Work
- Child Life & Creative Arts
- Integrative Health
- Chaplaincy
- Child Psych
- Pediatric Chief Resident
- QI Project Manager

## .PICUCares (EPIC SmartPhrase)

Type:  Service:  Date of Service:

☐ Cosign Required

Family Stress Screening & Response

Patient Name:

Room:

MRN:

Family/Caregiver Relation:

Stress Thermometer Score:

Main stressors for family:

Stress response protocol followed as marked below:

☐ Huddle with \_\_\_\_\_ (Charge RN or RN Leadership) and  
☐ Physician \_\_\_\_\_

☐ Safety concerns identified and discussed (if applicable):

☐ Family meeting recommended

☐ Support service referrals requested include:

☐ Social Work

☐ Child Life/Creative Arts Therapy

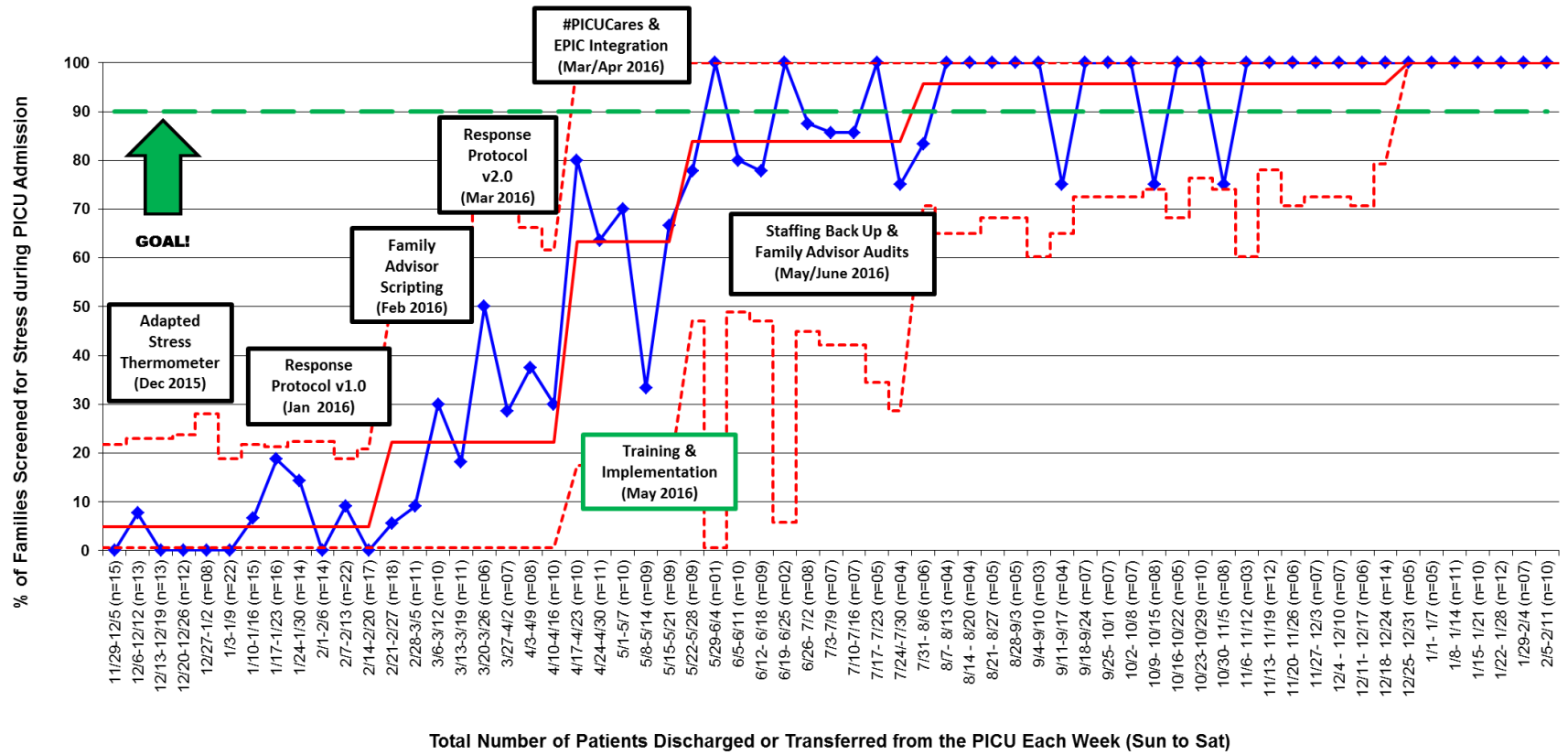
☐ Chaplaincy

☐ Integrative Health; IP consult placed in EPIC

☐ Other: \_\_\_\_\_

# % of Families Screened for Stress During PICU Admission

(updated 2/17/17)

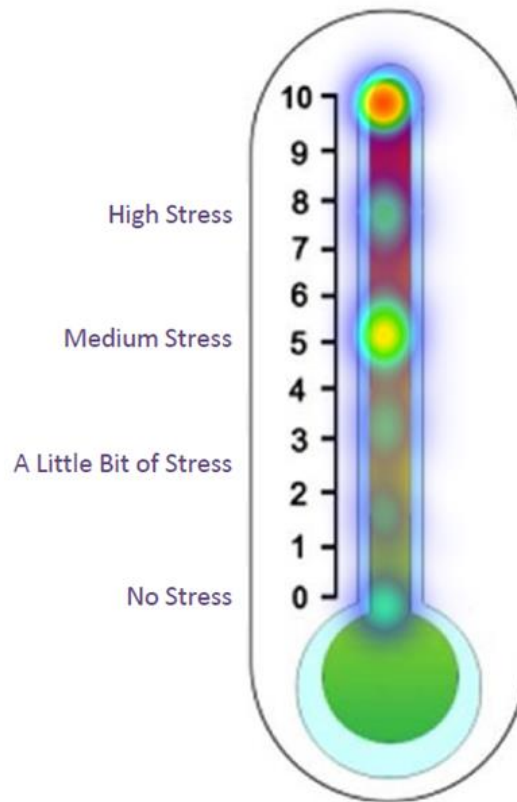


## Stress Thermometer: Our Family Partners

# Family Stress Thermometer - Heat Map

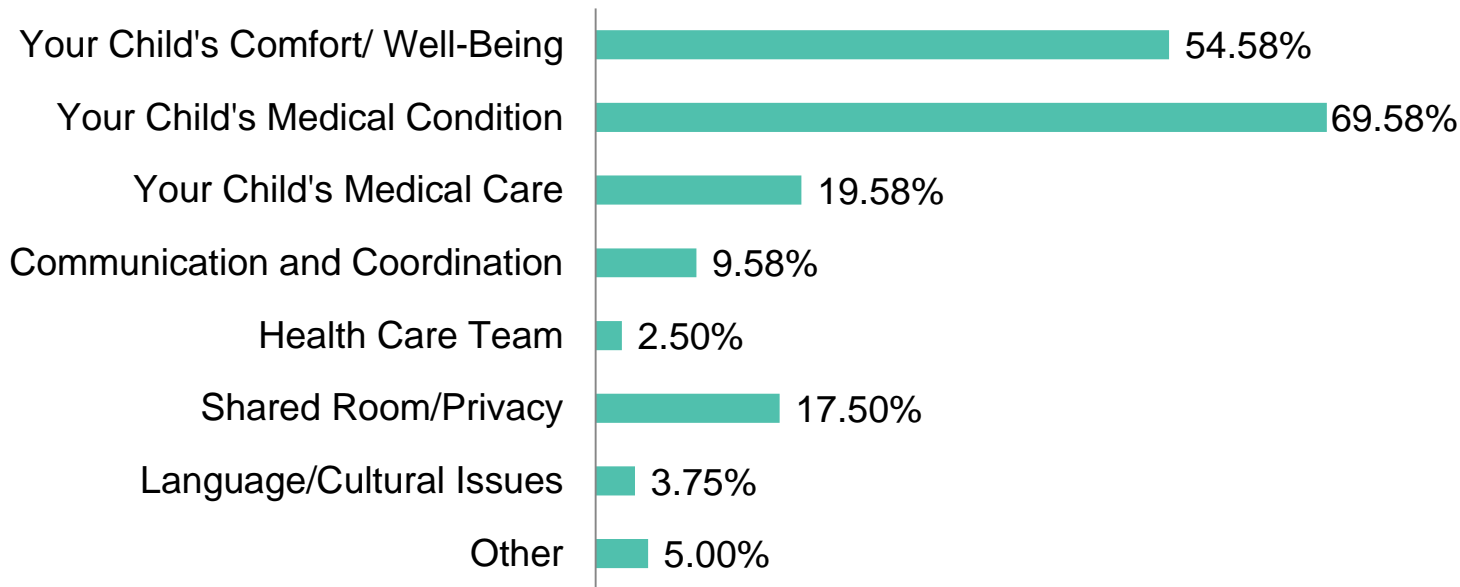
n = 415 family responses

<u>Stress Level</u>	<u>Frequency</u>	<u>%</u>
High Stress (8-10)	124	29.9%
Medium Stress (5-7)	111	26.8%
A Little Bit of Stress (2-4)	95	22.9%
No Stress (0-1)	85	20.5%

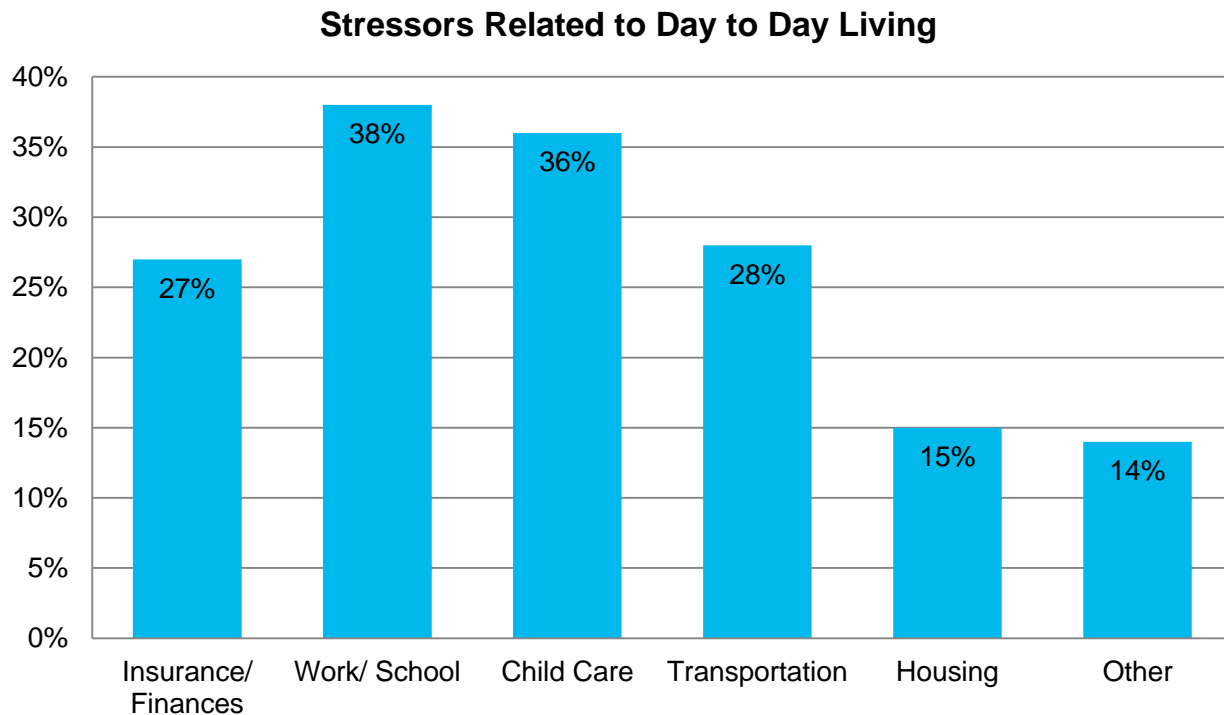


# Common Stressors: Child's Hospital Stay

## Stressors Related to Your Child's Hospital Stay

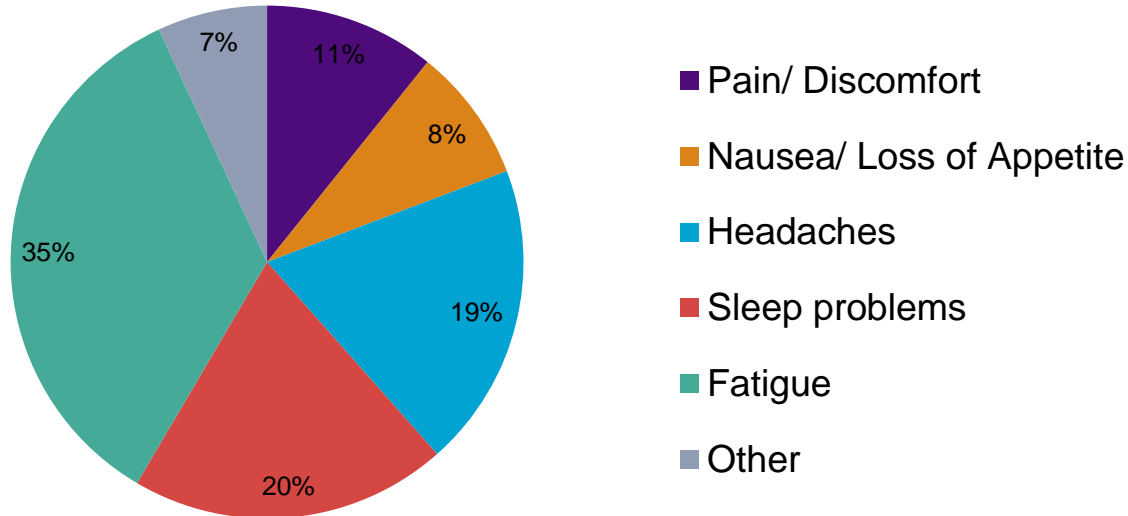


# Common Stressors: Day to Day Living



# Common Stressors: Caregiver Health

## Stressors Related to Caregiver's Health





# Common Stressors: Family, Relationships & Feelings

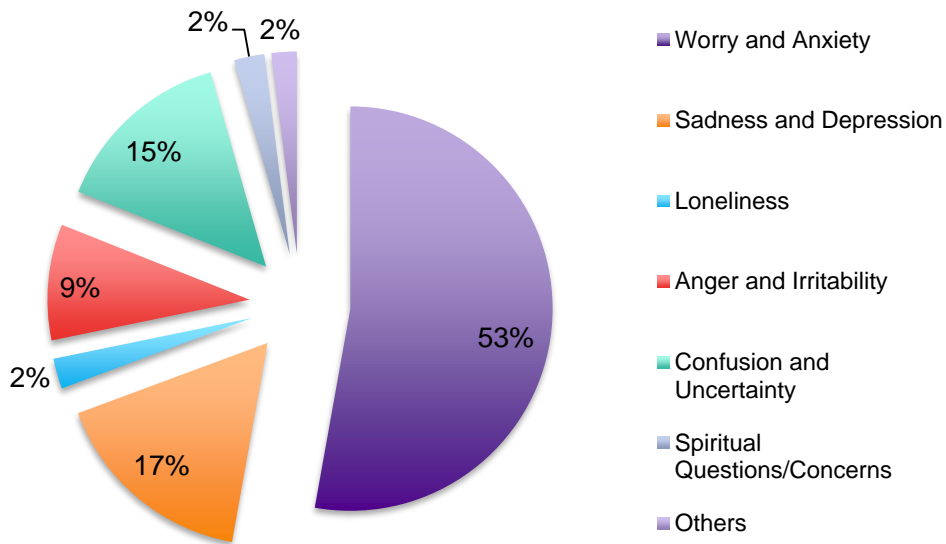
## Family and Relationships

- Partner/Spouse
- Children/Siblings

## “Good Catches”

- Postpartum depression / trauma
- Suicidal ideation
- Safety in the home

## Your Feelings



# Interdisciplinary Team Response

“Helping families manage stress or even noting their stress factors along with amazing care has made a positive impact on many families.”

- Senior Family Advisor

## Day 1

Parents assessed for stress:

**Mom: 10+**

**Dad: 10**

#PICUCares alert

**Huddle & Interdisciplinary Team  
Response**

## Day 2

Parents re-assessed for stress:

**Mom: 5**

**Dad: 3**

#PICUCares alert

**Huddle & Interdisciplinary Team  
Follow-Up**

## Day 3

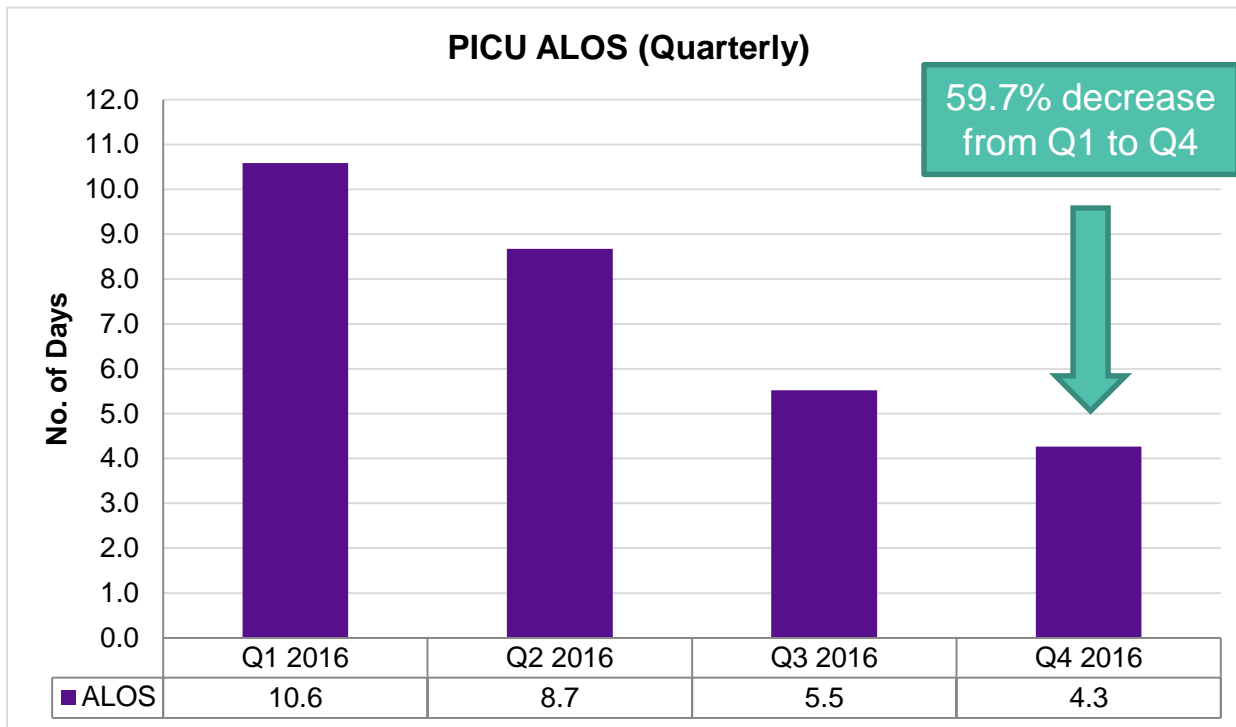
**Senior Family Advisor Check-In  
Interdisciplinary Team Support**

# Pre- and Post-Intervention Scores

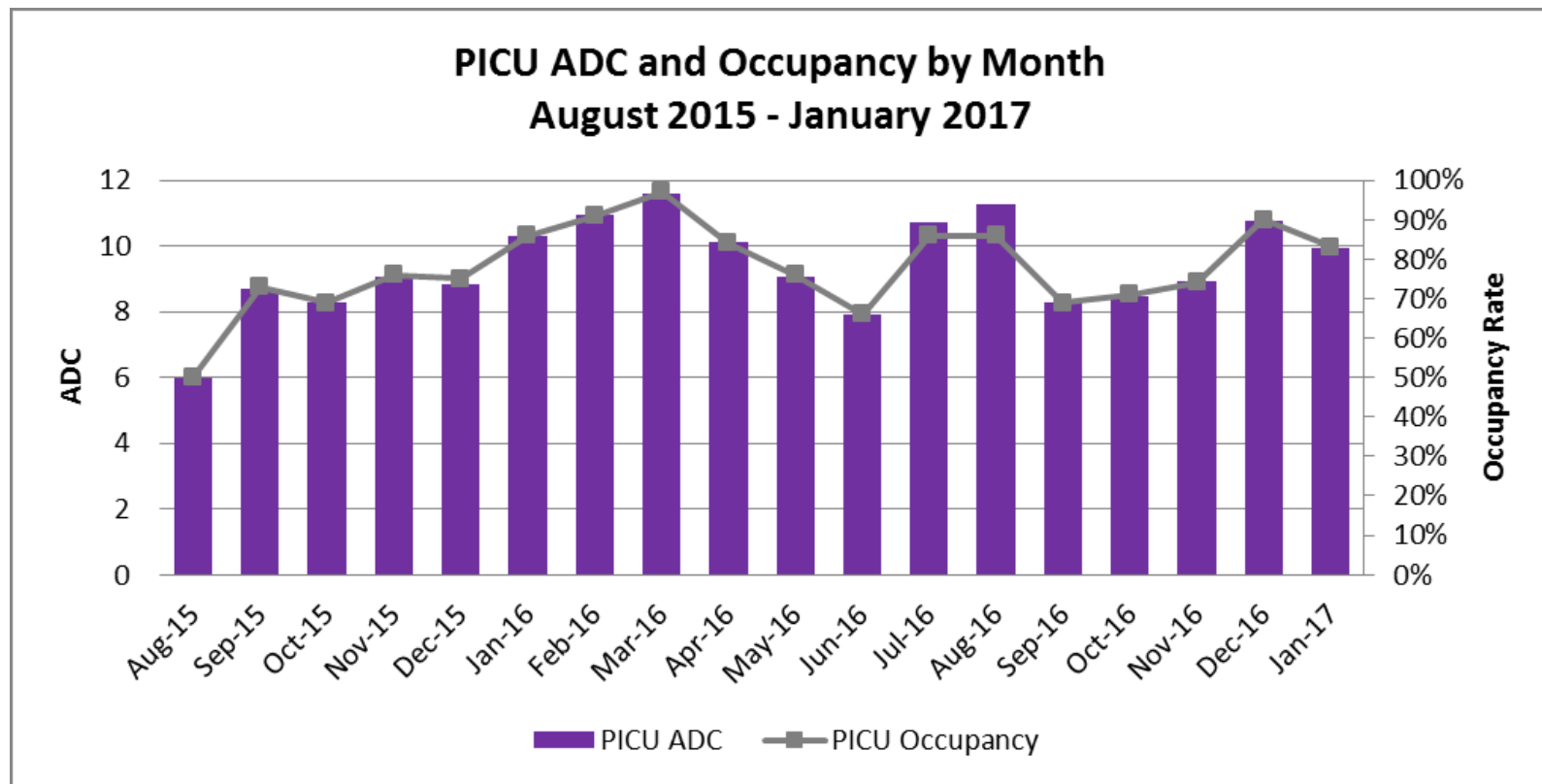
- There is evidence to suggest that families scoring 5 or higher (mean= 7.63, SD=1.92) experienced **statistically significant decreases** in stress scores ( $p < 0.0001$ ) after receiving support service interventions (mean= 4.30, SD= 2.19). The 95% confidence interval for the difference is 2.70, 3.95).

	Mean	N	SD	SEM
Pre	7.63	43	1.92	0.29
Post	4.30	43	2.19	0.33

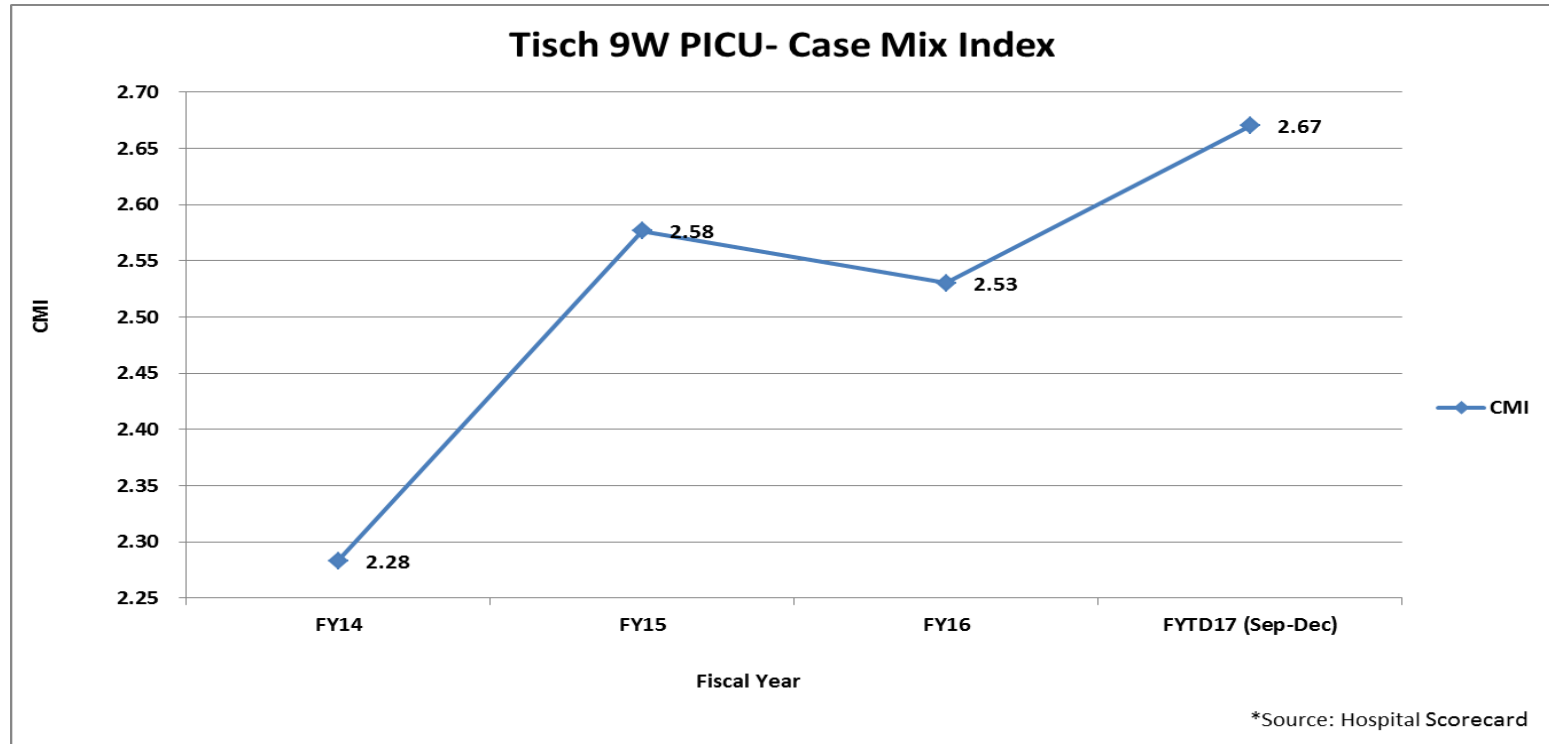
# PICU Average Length of Stay (ALOS)



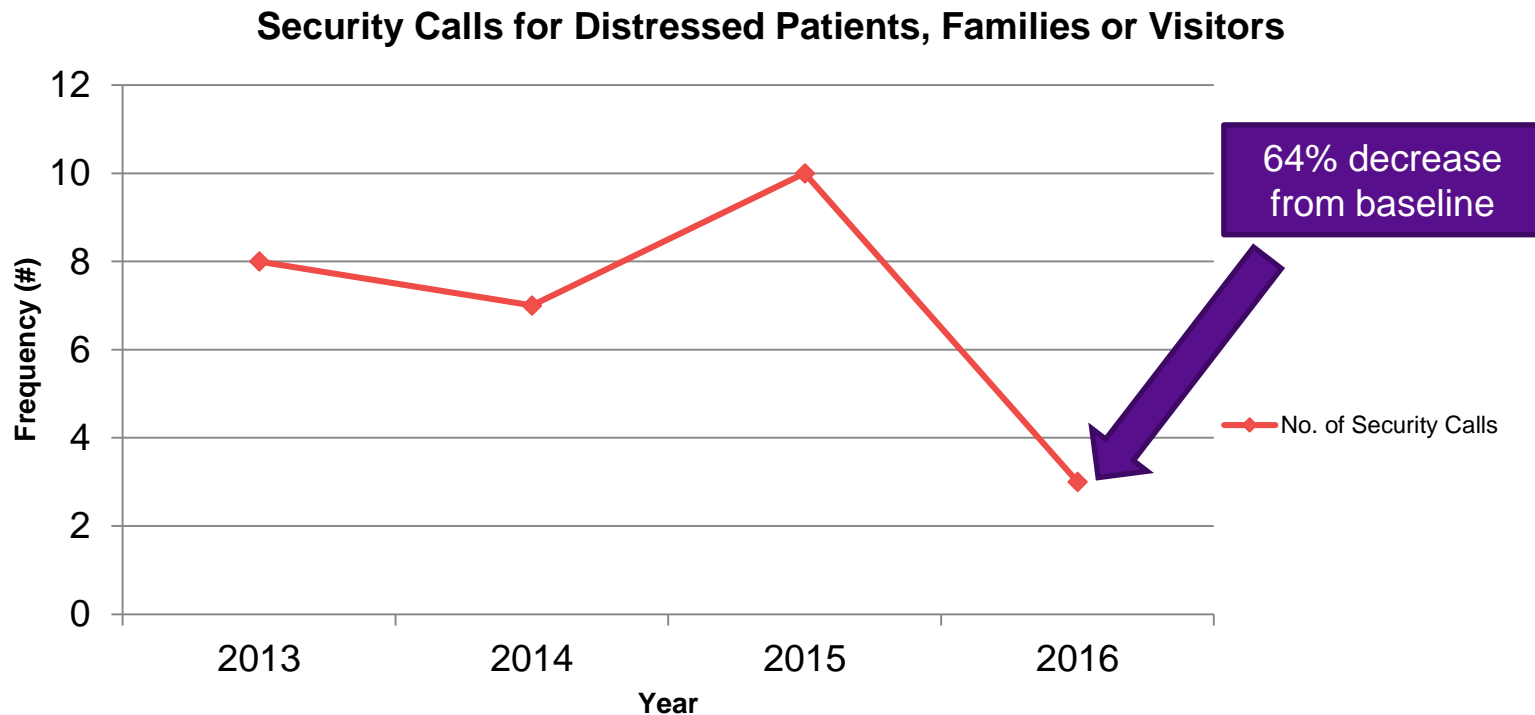
# Balancing Measure: PICU ADC & Occupancy



# Balancing Measure: PICU CMI



# Security Calls to Pediatrics



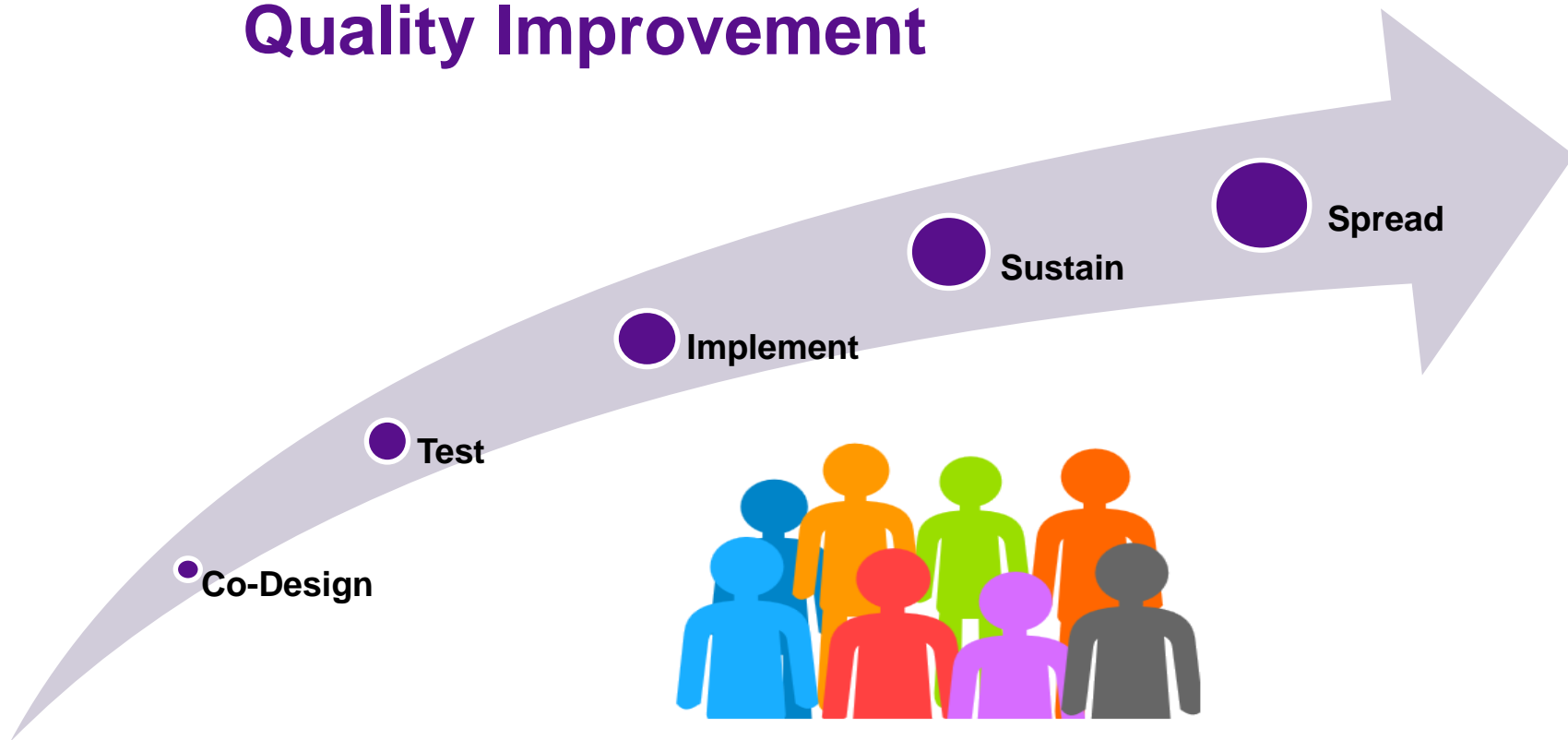


**“Relationships lie at the roots  
of resilience.”**

Suniya Luthar, PhD



# Patient & Family Engagement in Quality Improvement



**Patient and Family Engagement**

# Patient & Family Engagement in Quality Improvement



**Family Consultant**

**Family Education**



**Family Advisory  
Council (FAC)**

**Youth Advisory  
Council (YAC)**



**Senior Family  
Advisors**



**Cultural Diversity  
Advisors**



## Family Advisory Council (FAC)



## Youth Advisory Council (YAC)

# Senior Family Advisors & Family Faculty



# Great Interest – from Family Advisors

- Engaged and trained
- Using what they know
- Increasing impact
- A few more hours





# Senior Family Advisor Program

- Paid employees with valuable expertise
- 10 Advisors from the Family Advisory Council
- Diversity of Background
- Diversity of Experience



**Jennifer Daly, Senior Family Advisor**

**Stress Thermometer: Being Human**

# Engaging Families by Families

- You know your child best.
- We deeply respect your knowledge.
- We welcome you in all discussions about your child.
- We are here to listen and respond to your questions and concerns.
- We are ready to partner with you in your child's care, including safe care.





# Anticipatory Guidance in working with Senior Family Advisors

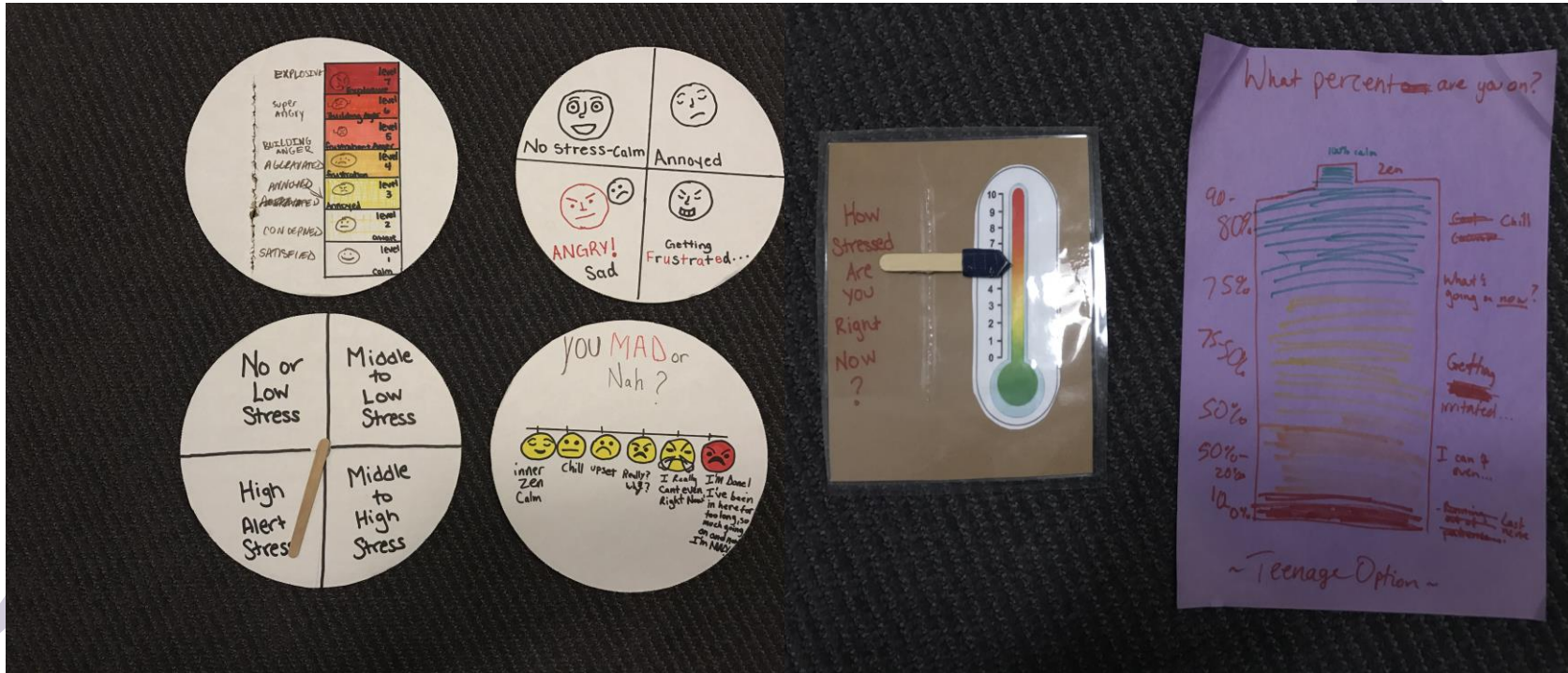
## For Clinical Teams

- The value of family perspectives
- How to engage families
- How families might be helpful

## For Families

- How to “jump in”
- Providing context
- Hearing about things going wrong

# Patient & Family Engagement in Quality Improvement



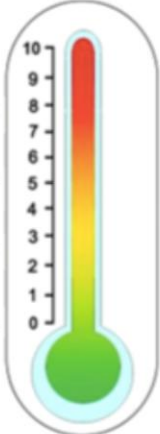
Patient and Family Engagement

# Co-Designed Family Stress Thermometer

**How are you doing? (Caregivers)**

When your child is in the hospital, it is natural for parents to feel stressed. If you are stressed, we want to support you.

In the thermometer below, please circle the number from 0 to 10 that best matches our stress level over the past 24 hours.



High Stress

Medium Stress

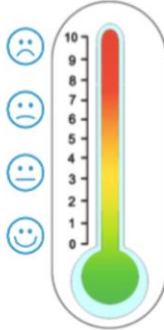
A Little Bit of Stress

No Stress

Caregiver #1: \_\_\_\_

Caregiver #2: \_\_\_\_

**HOW ARE YOU?**  
**TAKE 5:**  
**ASSESS YOUR STRESS**



10

9

8

7

6

5

4

3

2

1

0

Checking in with families early on about how they are doing shows that we care and opens the door for dialogue and support.

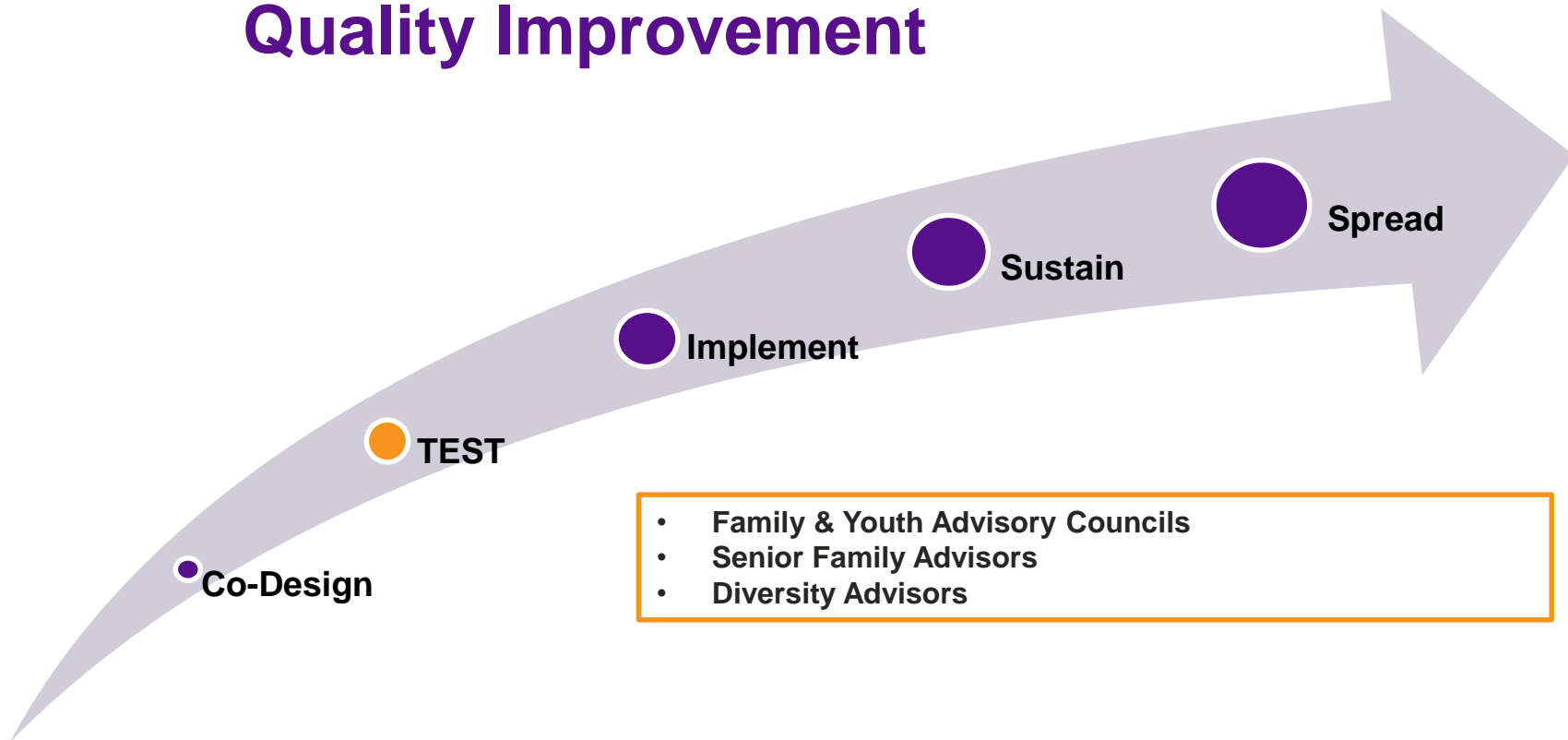
- *Senior Family Advisor*



How are you doing?  
¿Cómo se sienten?  
كده لاج فديك  
您現在感覺如何?  
Как вы себя чувствуете?

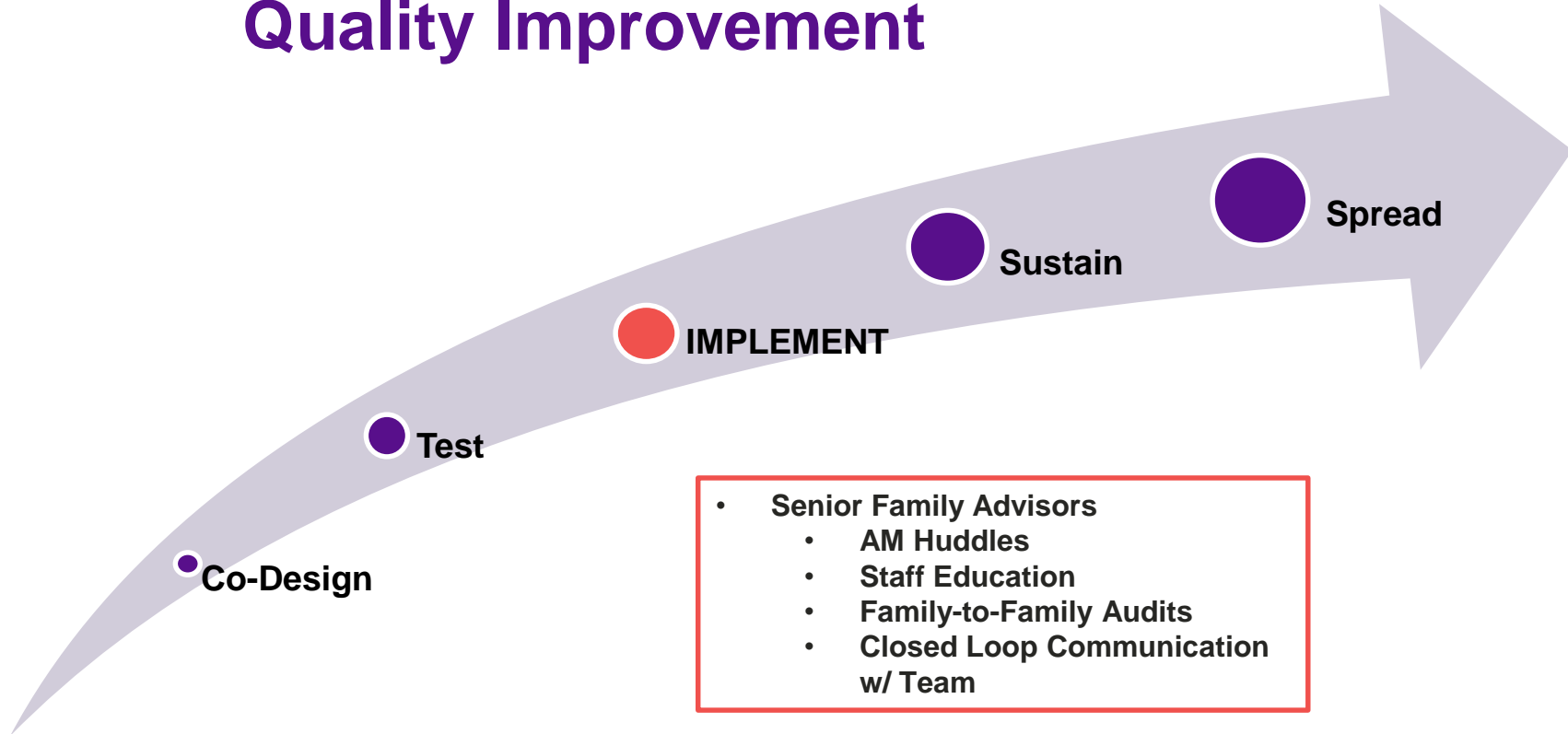
**NYU Langone**  
MEDICAL CENTER

# Patient & Family Engagement in Quality Improvement



**Patient and Family Engagement**

# Patient & Family Engagement in Quality Improvement



**Patient and Family Engagement**

# What Would Help to Decrease Your Stress?

*“Learning about how to care for my child and being able to look for signs following discharge”*

*“To know my child will be as back to normal as possible”*

*“Not having to miss work next week”*

*“The more information I have to understand, the less stress I feel”*

*“Feeling less helpless about my child’s pain”*

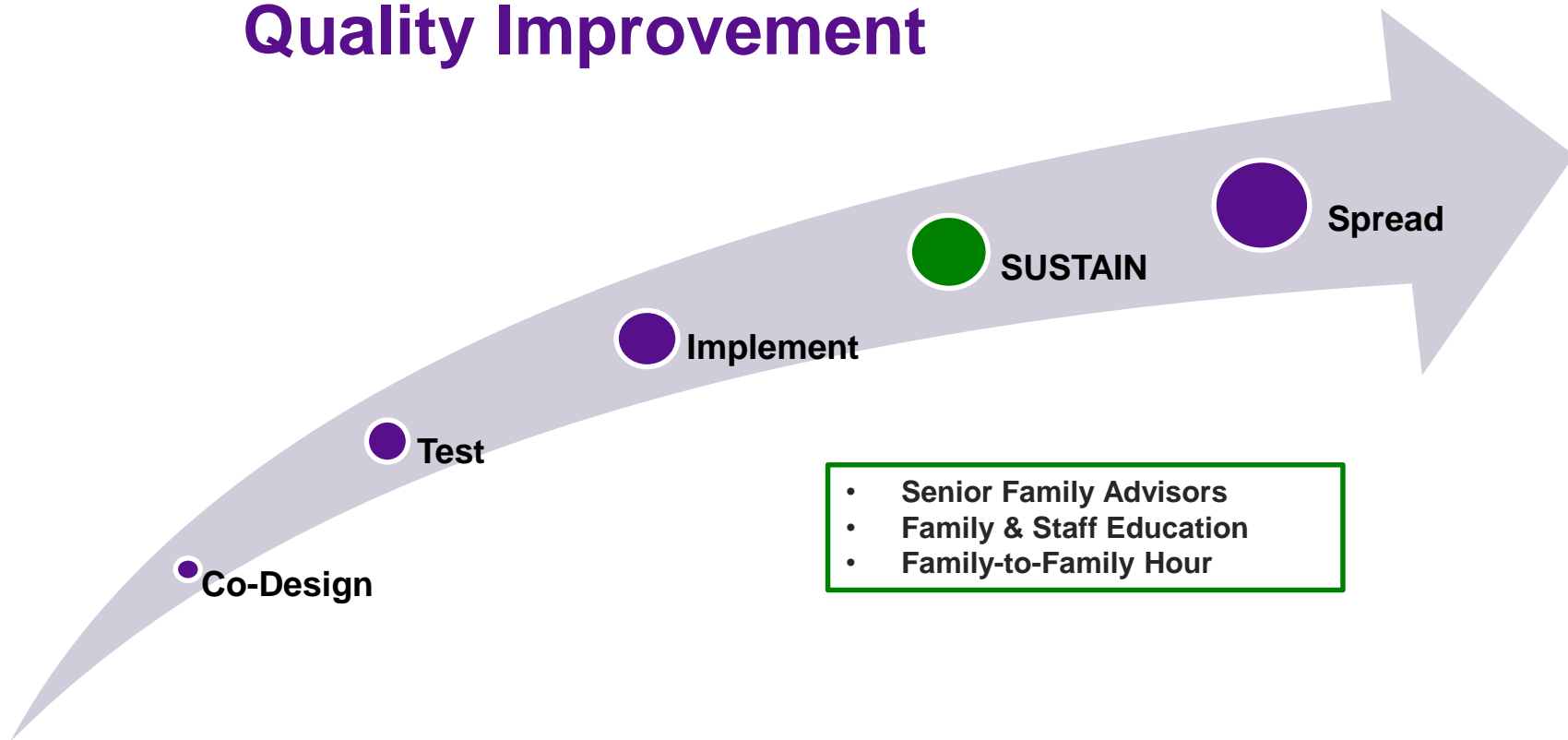
*“Understanding my own coping style”*

*“Helping my wife (baby's mother) will help me”*

*“Talk with a strong and warm person from community”*

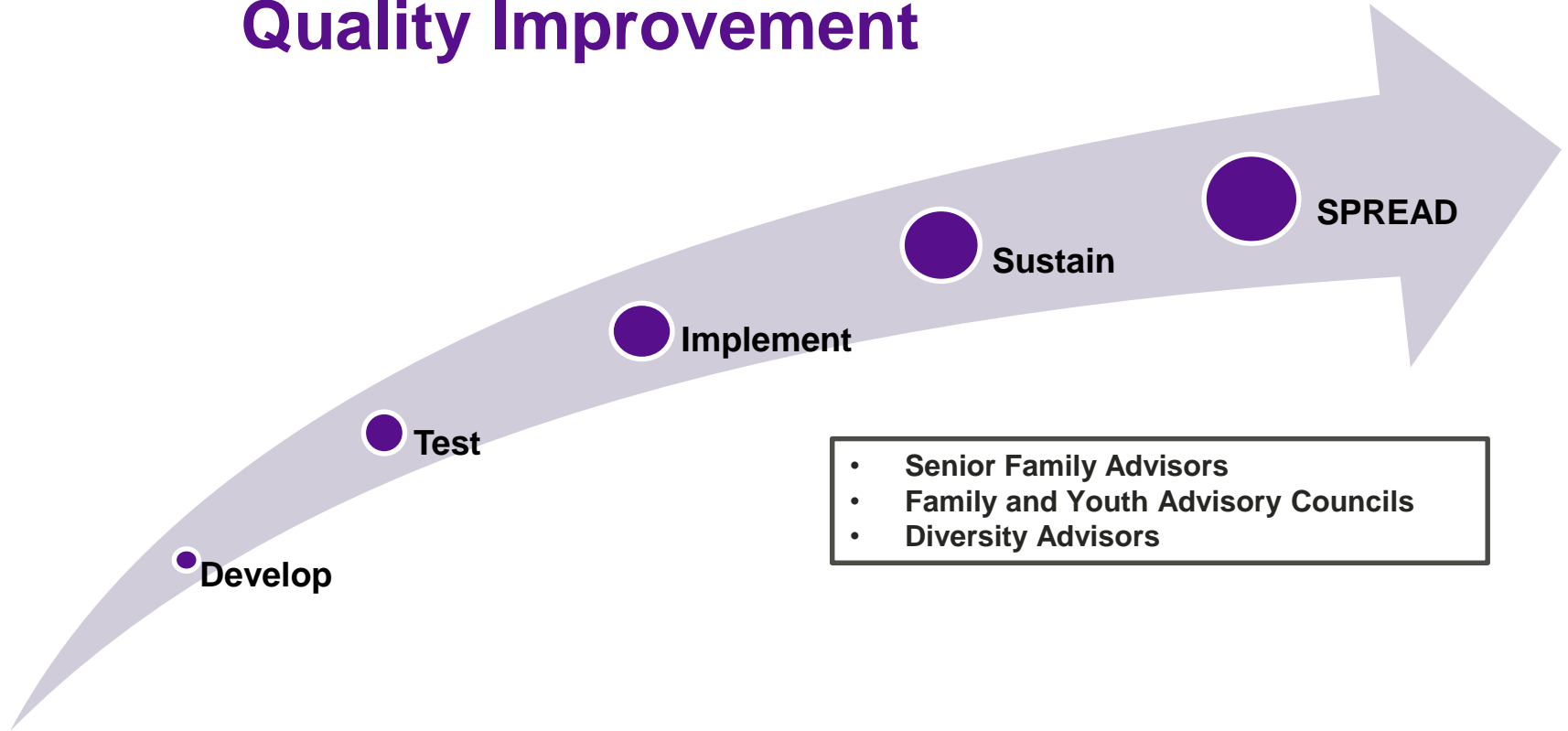
*“Getting help for my child's mental health care”*

# Patient & Family Engagement in Quality Improvement



**Patient and Family Engagement**

# Patient & Family Engagement in Quality Improvement



**Patient and Family Engagement**



**Stress Thermometer: The Family Partner Role**

## Lessons Learned

- Family advisors and nursing champions played crucial and complementary roles in the success of this improvement initiative.
- Interdisciplinary team collaboration led to reliable and sustainable improvement even in the context of increasing acuity, complexity and staffing changes seen in the PICU.

# Challenges & Opportunities

Ongoing challenges and opportunities include:

- 1) Integration of new processes and tools into the electronic health record and systems-level workflows
- 2) Interactive, interdisciplinary models of providing staff education
- 3) Streamlined data collection of process and outcome metrics

## Next Steps

- Current adaptation and spread to the congenital cardiac ICU and system-wide by year end
- Development of a Stress Thermometer mHealth app with EPIC integration
- Evaluate program impact and outcomes measurement

# QUESTIONS & DISCUSSION



# Thank you!

- Presentations:  
[www.childrenshospitals.org](http://www.childrenshospitals.org)
- Presenter contact information:
  - [Ron-Li.Liaw@nyumc.org](mailto:Ron-Li.Liaw@nyumc.org)
  - [Beth.Silber@nyumc.org](mailto:Beth.Silber@nyumc.org)