

Transitioning From NICU to Home: Understanding & Supporting Home Sweet Home



*Elisabeth C. McGowan, MD
Associate Professor of Pediatrics
Warren Alpert Medical School of Brown University
Medical Director WIH NICU Follow Up Program
January 2026*

Disclosure

- No financial interests or conflicts of interest to disclose

Objectives

- Identify and discuss the complexities of the home environment as it pertains to high-risk NICU families, and biological pathways that may be influence developmental outcomes.
- Review how transition-to-home programs can be utilized to understand families & provide enhanced services.
- Discuss potential opportunities that incorporate families (both pre & post discharge) that may help mitigate the environmental risks that affect neurodevelopmental delays.

Outcomes - medical & social risks



- Biologic exposures (BPD, sepsis, IVH, etc) associations with poor outcomes ^{1,2}
 - Brain injury persistent, long-term sequelae.
- Environmental exposures play critical role
 - Low SES risk factor
 - Higher SES may mitigate³
 - Some SES variables assume increasing importance over time¹

Continue to explore the interplay of these relationships and effect on neurodevelopmental outcomes among all those high-risk infants.

¹Doyle LW et al, Pediatrics 2015;² Luu TH et al, Pediatrics 2011;

³ Benavente-Fernandez I et al, Ped Research 2019

WIH Follow Up Program 1974 - 2025

1970-90's → Preterms < 32 weeks, < 1500g
Medical Risks

2010 → Moderate PT (32 1/7 – 33 6/7)
Socio-economic & psychosocial risks

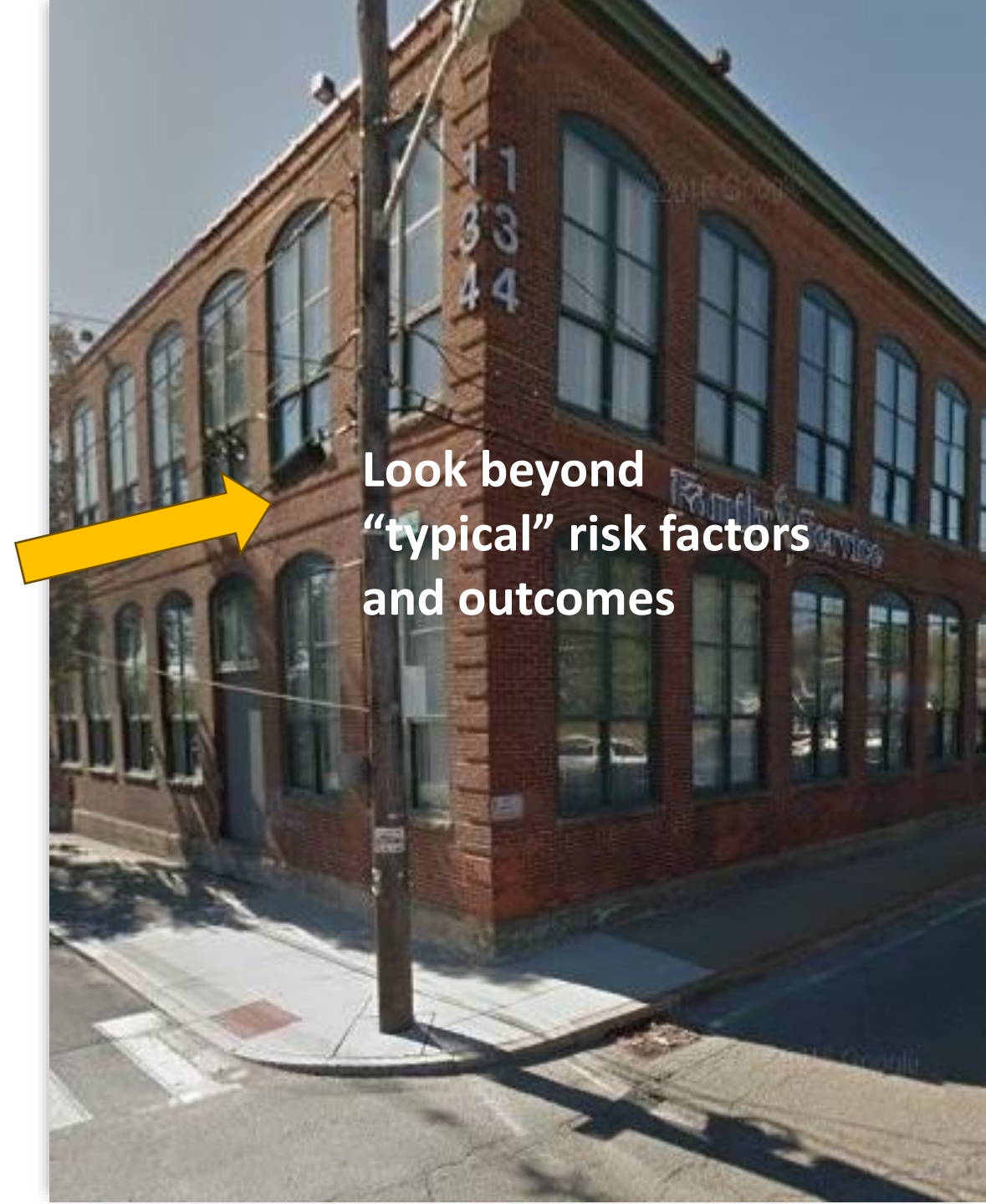
2020 → HIE (mild, mod, severe)

Staff


- 3 Neos, 1 Pedi, 2 FNPs, 2 psychologists, MA
- data analyst, 2 SW, clinic manager & admin

Assessments (Mon-Th)

- 1m, 3m, 7m, 1y, 2y, 3y, 5y (+/- 7-8y)



Rationale for enhanced Transition Programs

- Many PT infants have multiple SHCN @ NICU discharge.
 - ~ 10% births are early PT, associated costs ~ 26 billion/yr.
 - Up to 50% of early PTs are hospitalized w/in first 18 months life.
- 
- Complex home environment influences neurodevelopmental outcomes
 - socioeconomic, psychologic & physical
 - Transition Home programs nationally recognized
 - AAP- Assessment of social risk factors & parent mental health prior to d/c
 - NPA – NICU discharge guidelines (anticipatory guidance, family & home needs assessments, transfer & Coordination of care).



WIH THP

- 2006 conceptualized & pilot data
- 2012 \$ 3.2 M CMS Innovation Challenge Grant

- Identify and address

- Medical & health care disparities associated with adverse outcomes.
- Optimize care by partnering with community services & medical home.
- ↓ unnecessary ER visits & re-hospitalizations
- ↓ overall healthcare costs
- Improve overall outcomes for infant & family

Influence of environment on outcomes



COMPLEX ENVIRONMENT

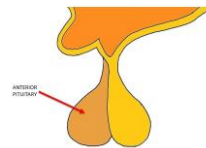
SES – income, education level, jobs, insurance

Family – parenting style, enriched environments, mental health, ACEs

Neighborhood – safety, racism, schools, community centers, pollution, green space



Alters brain growth
structure & functional
delayed vs different ?



Early life stressors →
“allostatic load”
prolonged activation
HPA—axis



Alterations in gene
expression
DNAm



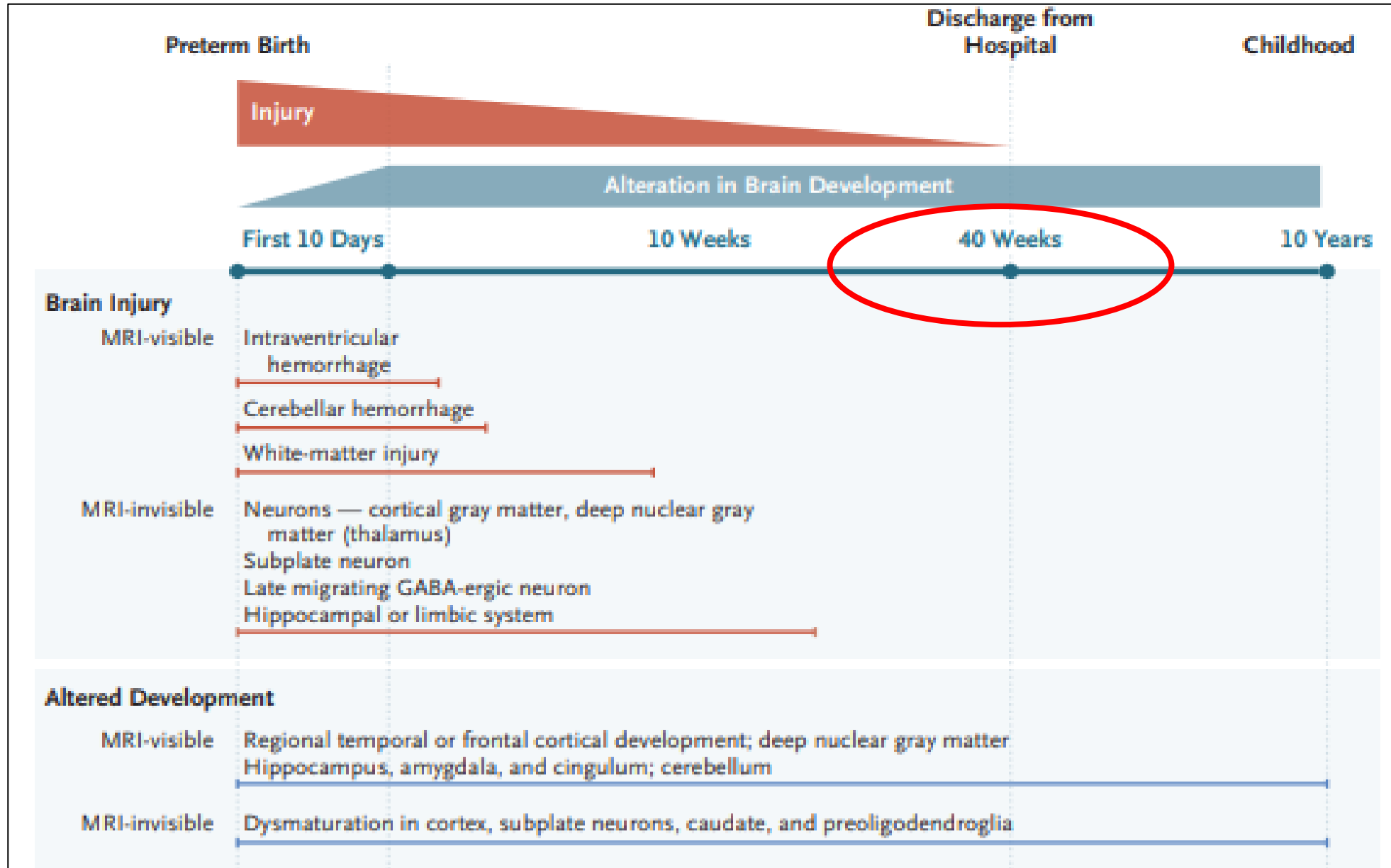
Microbiome →
neurogenesis,
myelination, HPA axis,
WM maturation

Cognitive, language, motor, behavioral, academic development

What about the
brain of the
infant born
preterm ?



Timeline of brain vulnerabilities that lead to poor neurodevelopment



WIH Transition Home Program (THP)



Enrollment

Eligible:

*RI Medicaid families
NICU stay > 5d, all GA
English/Spanish*

Approach & Enroll in NICU:
medically stable

Follow
*weekly NICU rounds
Until 7 mos CA*

NICU

*2 Social Workers
(1 trilingual)*

Perform:

*family assessments
psychosocial stressors
Mental Health (EPDS)*

Provide:

*Education Binder
Attend family mtgs
Frequent check- ins
(2-5X/wk)*

D/C transitioning

Identify discharge barriers

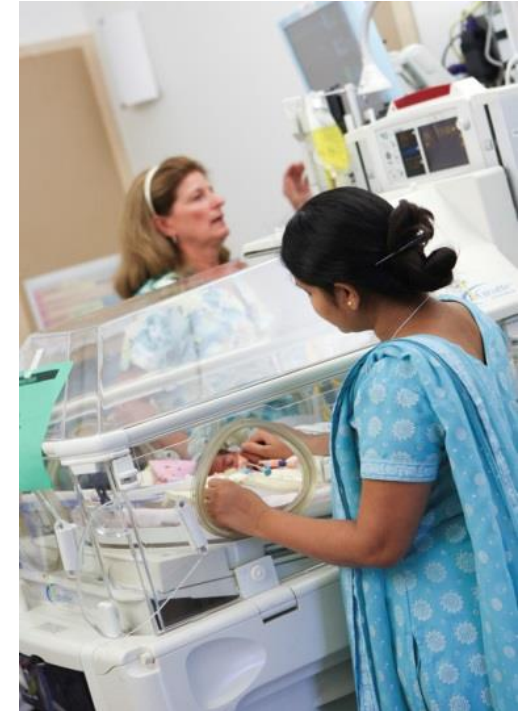
- *child care, work schedules*
- *Home visit
safety, utilities, supplies*

Assess health literacy

- *WIC, formula mixing,
financial resources*
- *review medical calendars*

Assist

- *Safe Baby Court*
- *Review medical calendars*



WIH Transition Home Program (THP)



Post Discharge (until 7 mos CA)

24 hrs SW call, 1 wk NP home visit
24/7 on call (SW, MD)
Standard FU visits (1,3,7 mos)
Telemedicine visits
EPDS 1 mos post d/c

Provide:

referrals community services (*food banks, clothing*)
assistance w/social services (*SSI, WIC, food stamps*)
Transportation (*ubers*)

Infant care items

diapers, wipes, strollers, pack-n-play

Liaison: *w/VNA, EI, PCPs, subspecialist*

Transition to Standard FU Clinic

1, 2, 3, & 5y assessments

Community & social assistance (SW)



How did we get
Medicaid to fund
our THP program ?



Early Results of THP

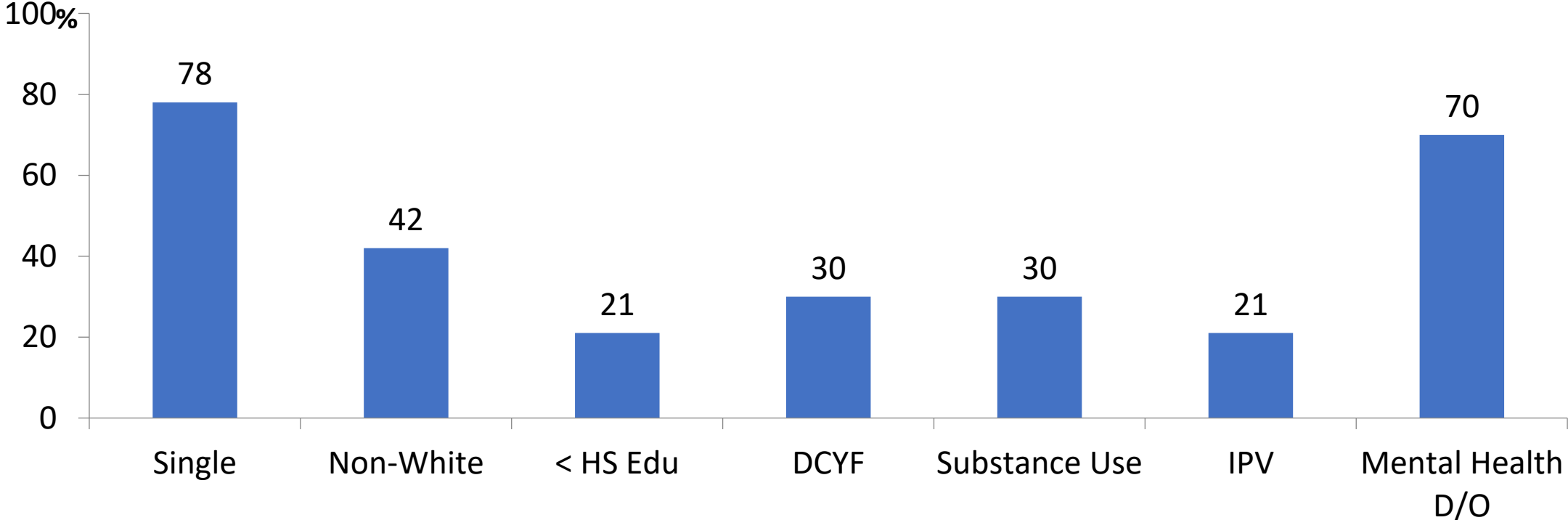
- THP program (Y3 vs Y1)¹
 - 34% ↓ in ER visits (90 days post d/c)
 - 43% ↓ in re-hospitalizations
- Cost-benefit analysis THP services & medical spending²
 - Medicaid savings (2012-2014)
 - \$ 4,600 per infant per quarter
 - \$18,000/yr

Children's Emergency

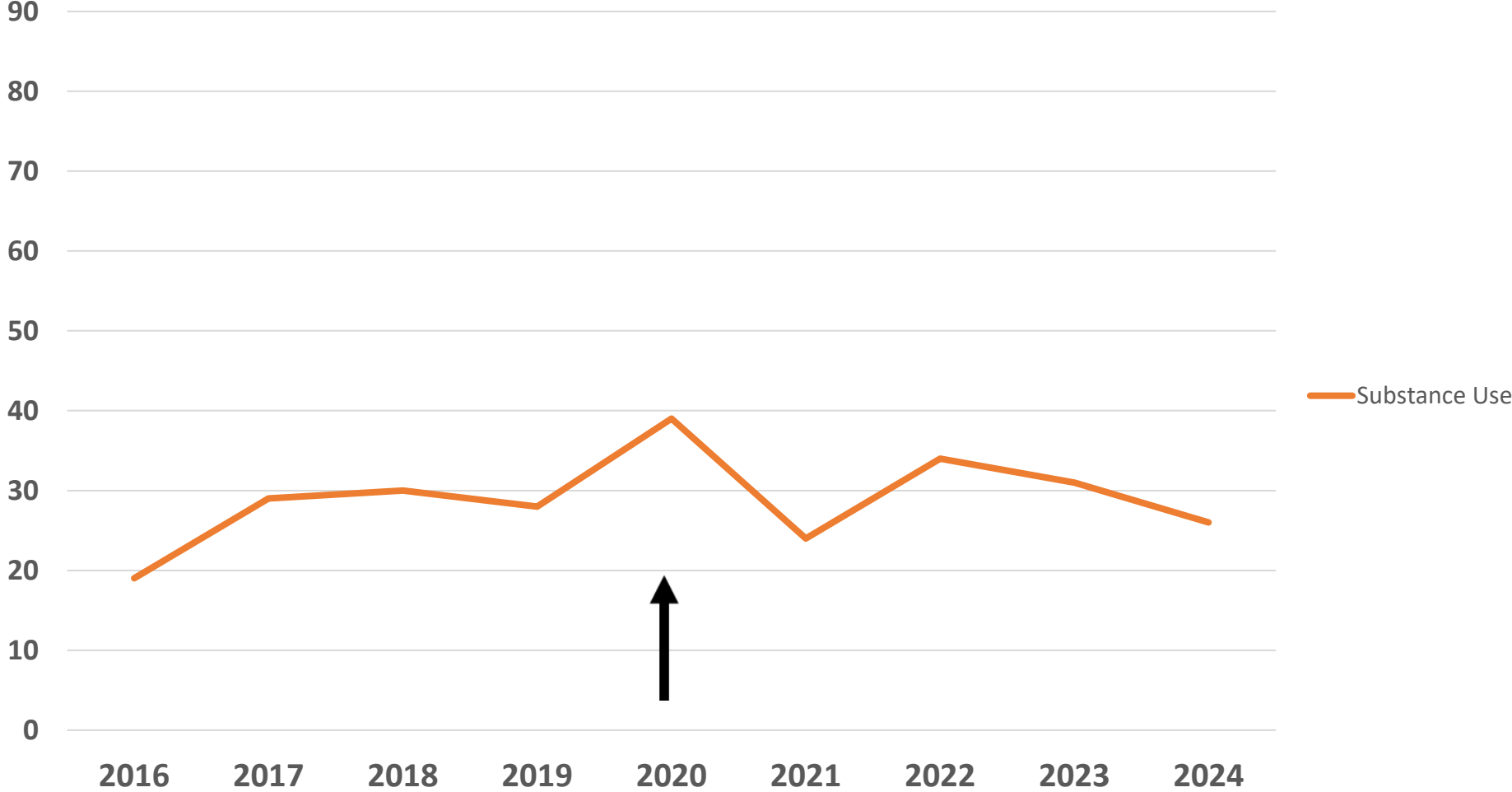
¹ Vohr BR, et al J Perinat 2017 ² Liu Y, et al J Peds 2018

THP Families

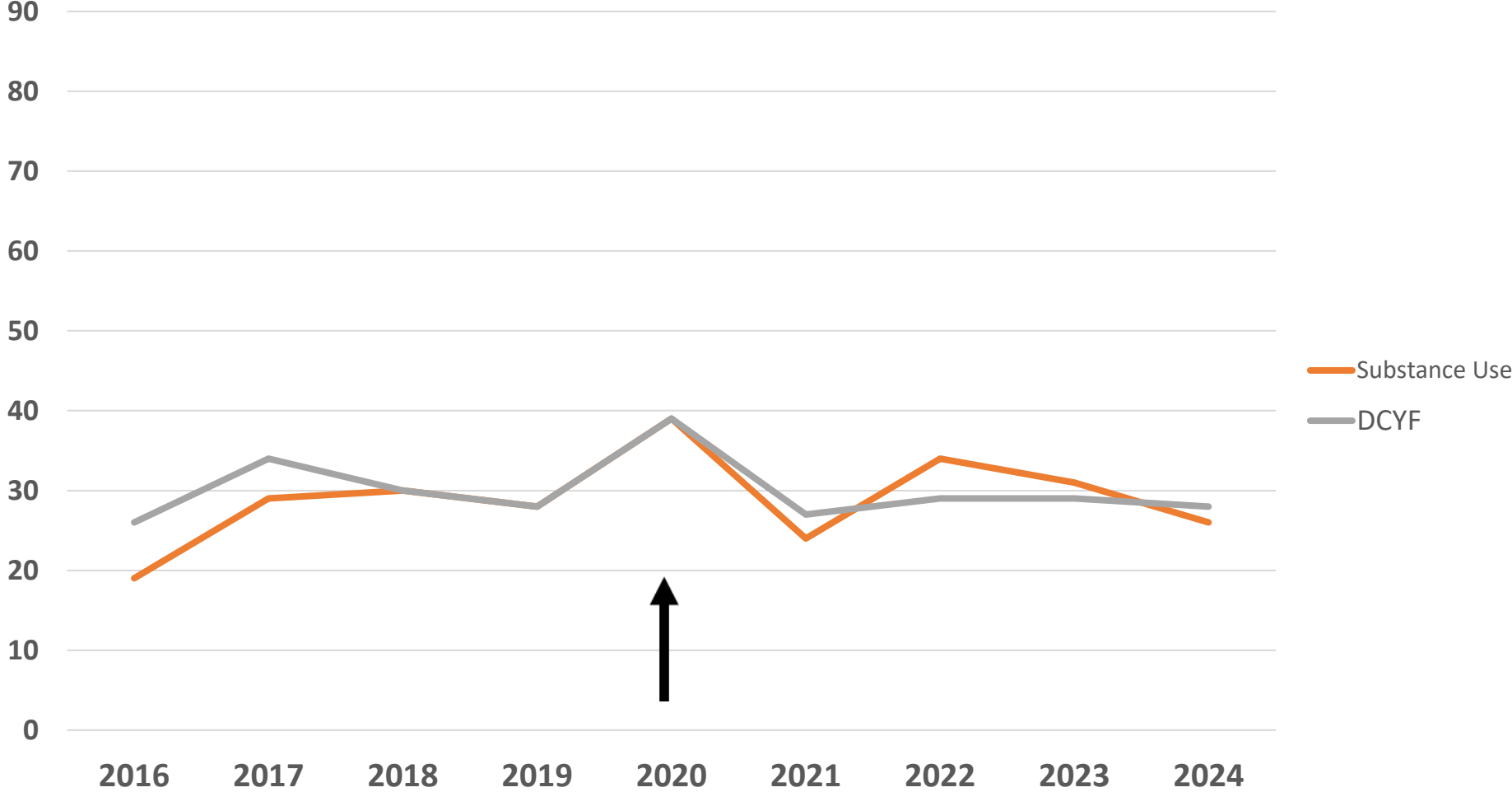
2022– 2025 (n= 254)



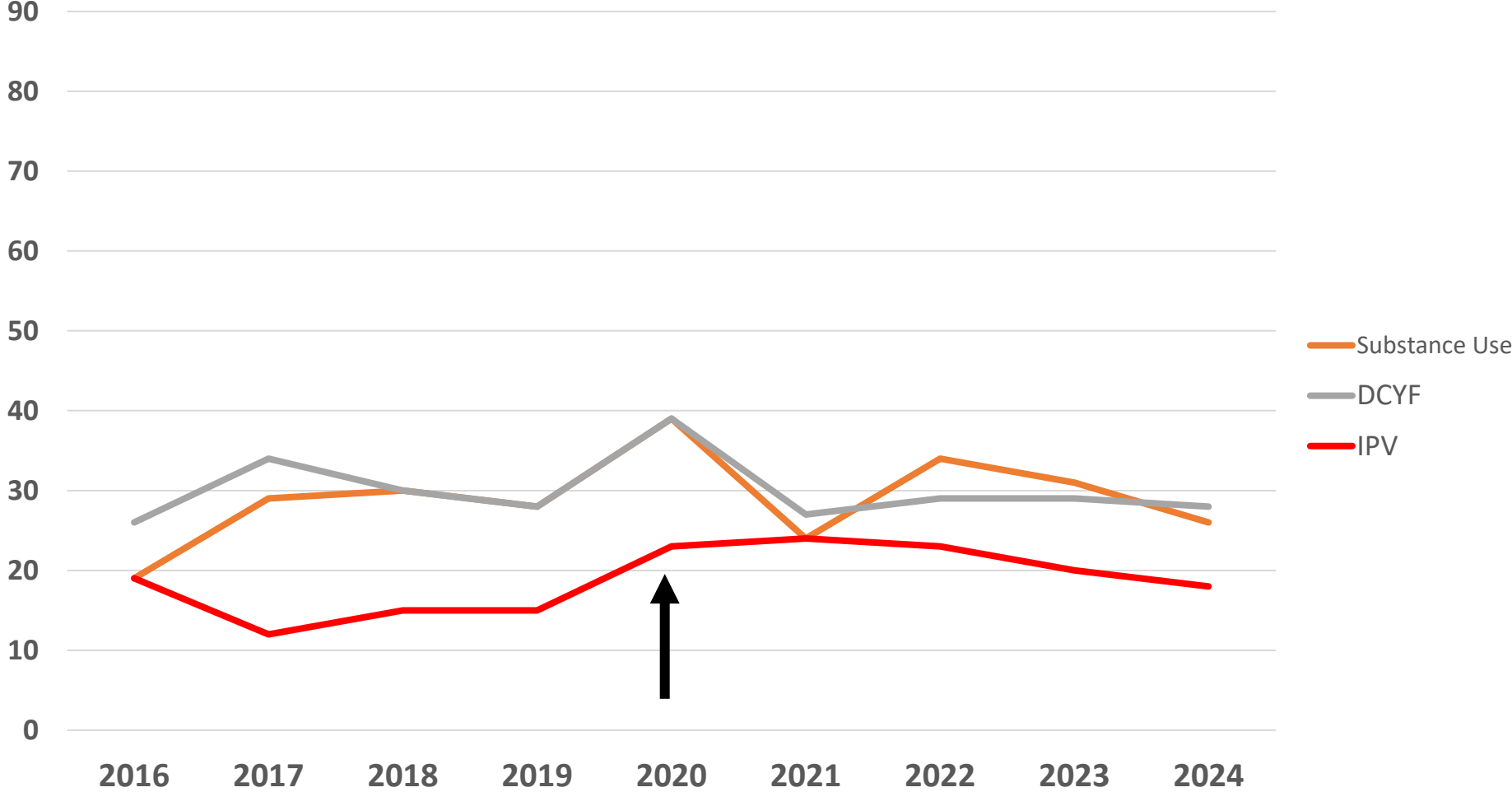
Percent of WIH THP mothers with psycho-social risks 2016-2024



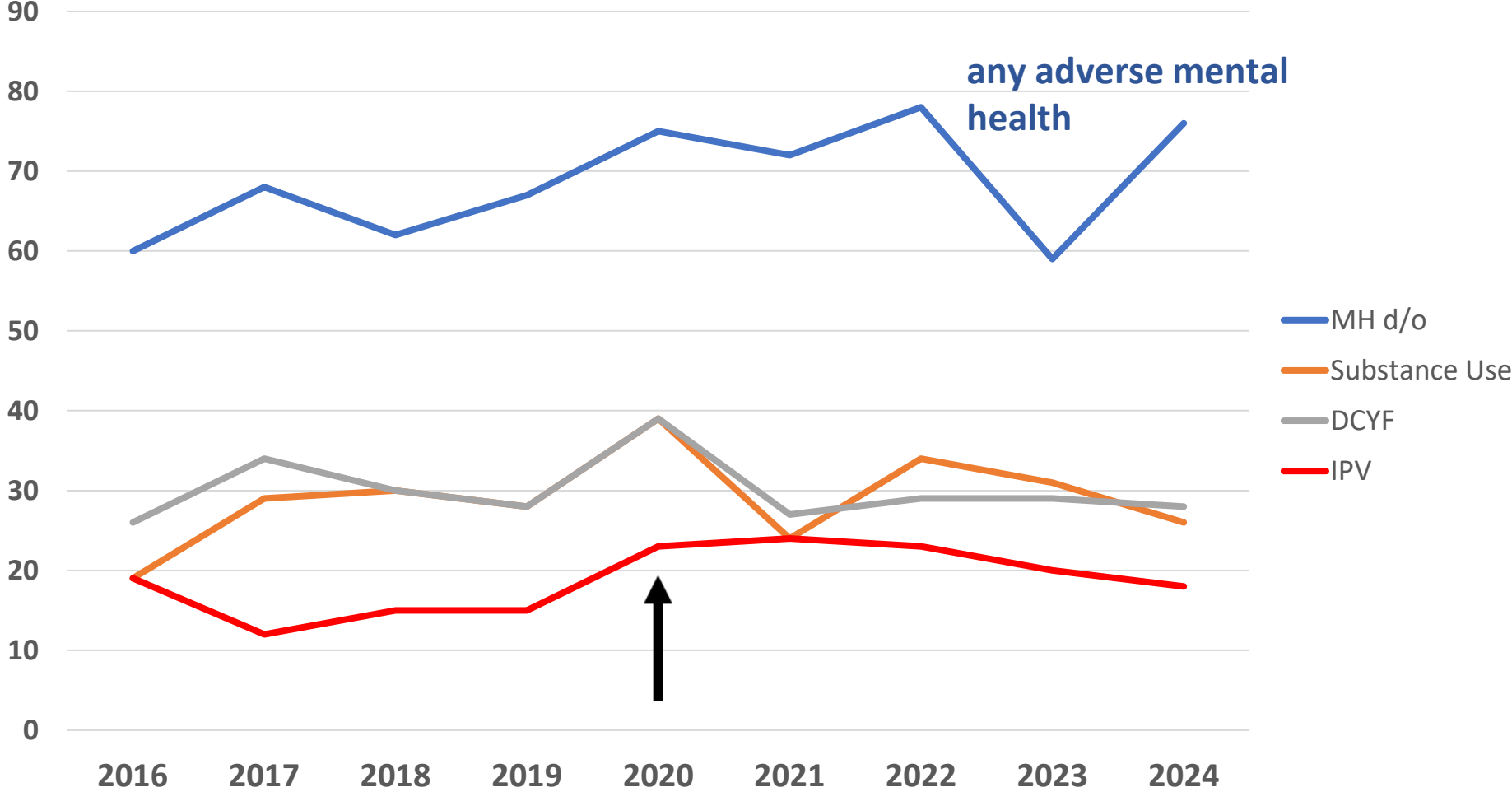
Percent of WIH THP mothers with psycho-social risks 2016-2024



Percent of WIH THP mothers with psycho-social risks 2016-2024



Percent of WIH THP mothers with psycho-social risks 2016-2024



Maternal MH & Discharge Readiness



Fragile Infant Parent Readiness (FIPRE) Questionnaire

- Mother w/a history of MH disorder
 - 1.5-2x more likely to have negative perception of well-being infant aOR 1.56
 - self aOR 1.99 @ NICU discharge¹
- Mothers w/MH disorder and negative perceptions at discharge
 - ↑ scores on EPDS @ 1 mos post-discharge²
 - ↓ competency (aOR 3.23)

SW increased efforts on addressing MH & supporting parenting skills

Predictors of ER visits

Vohr BR et al, J Perinatology 2017

Methods: 954 THP infants (< 37wks), enrolled in Current Care (state wide data base, real time ER alerts)
ER use @ 90 days



	aOR* (95% CI)	p
BPD	3.26 (1.87 – 5.69)	<.0001
Mothers Non-English Speaking	1.68 (1.01 – 2.79)	.04
Mothers Mental Health d/o	1.55 (1.05 – 2.27)	.02
THP program (Y3 vs Y1)	0.66 (0.46-0.96)	.04

24/7 physician/SW on call

* adjusted for GA, Medicaid, multiple birth, < HS education

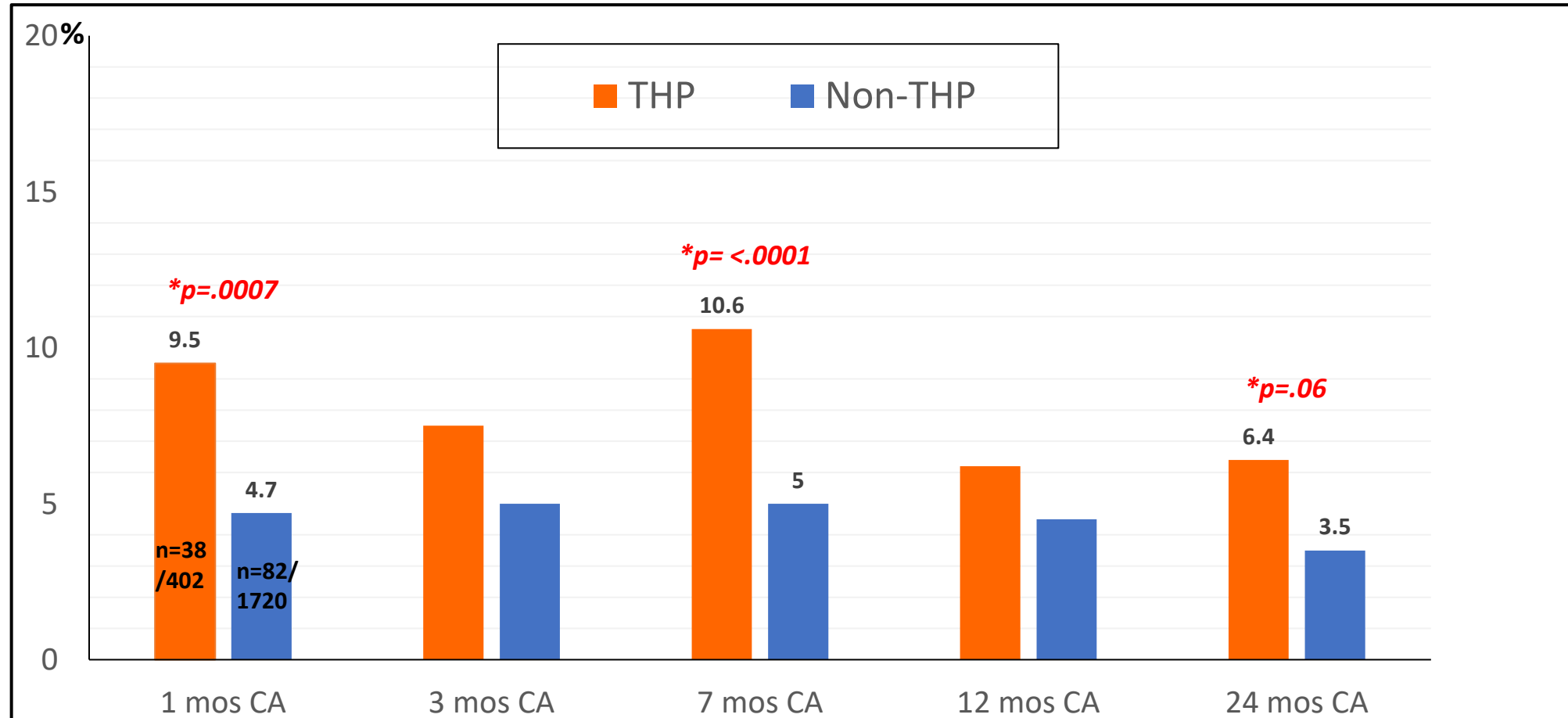
Food Insecurity (FI)

- 2015 AAP Promoting Food Security for all children
 - screening, addressing & educating
- Risk factors
 - Poverty, single caregiver, child < 6 years, family member w/disability
 - Minority race/ethnicity
- Consequences¹
 - Medical → low BW, birth defects, iron deficiency anemia, cardiometabolic risks²
 - Academic → poor performance
 - Behavioral, social-emotional, mental health problems
 - Indirect effects of chronic stress/worry



FU Clinic Food Insecurity Screen Positives

Infants < 34 wks or ≤1250 g (2018-2024)



Addressing Food Insecurity

SW work closely w/families to ensure access food

- Help parents enroll (pre-discharge or post-discharge)
 - WIC
 - SNAP
- Provide formula (and coupons)
- Updated lists of RI & SE Mass food pantries
- Supermarket gift cards



High Risk (HR) Neighborhoods



BROWN
School of Public Health

Maternal address @ time birth → census block group



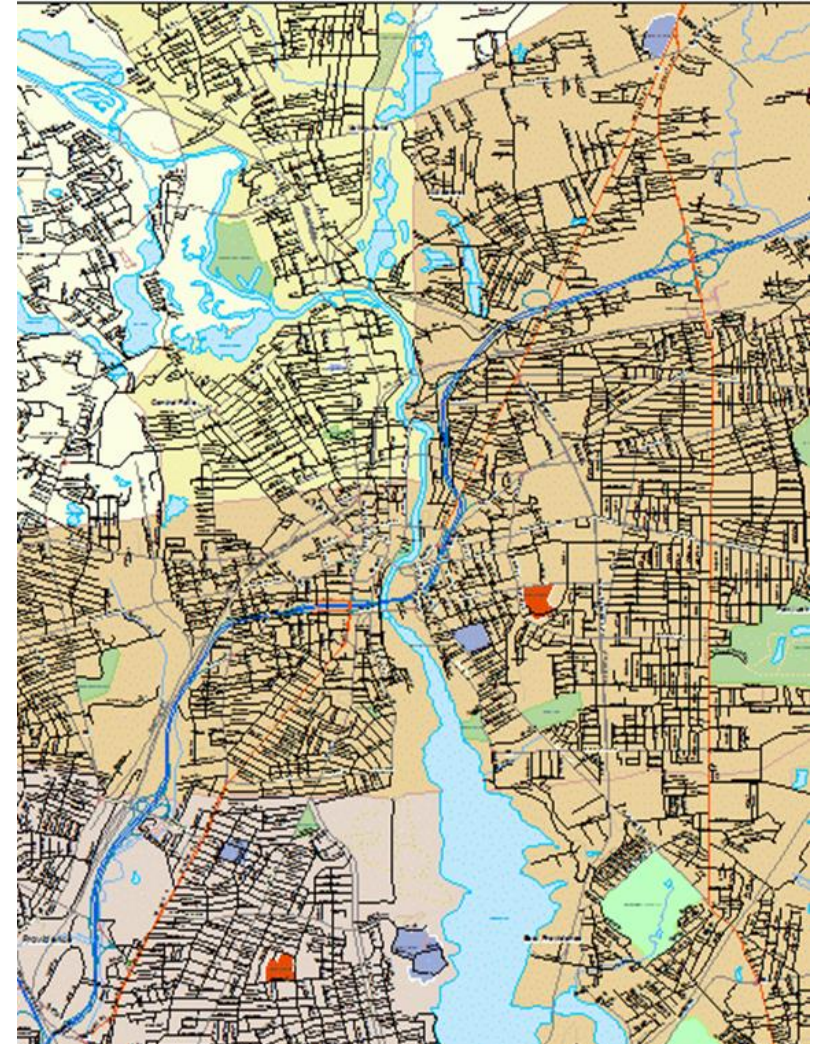
*% adults w/o HS education, single-parent,
household data, poverty¹*



Scale range (8-40)

High risk define $\geq 75^{\text{th}}$ % block groups

*** *considerations: cannot establish causality, bias (LTF), address may change*



¹ Neighborhood RI 2012 – 2016 American Community Survey

High Risk (HR) Neighborhoods & outcomes



BROWN
School of Public Health

Infants born in HR neighborhoods @ 2 years

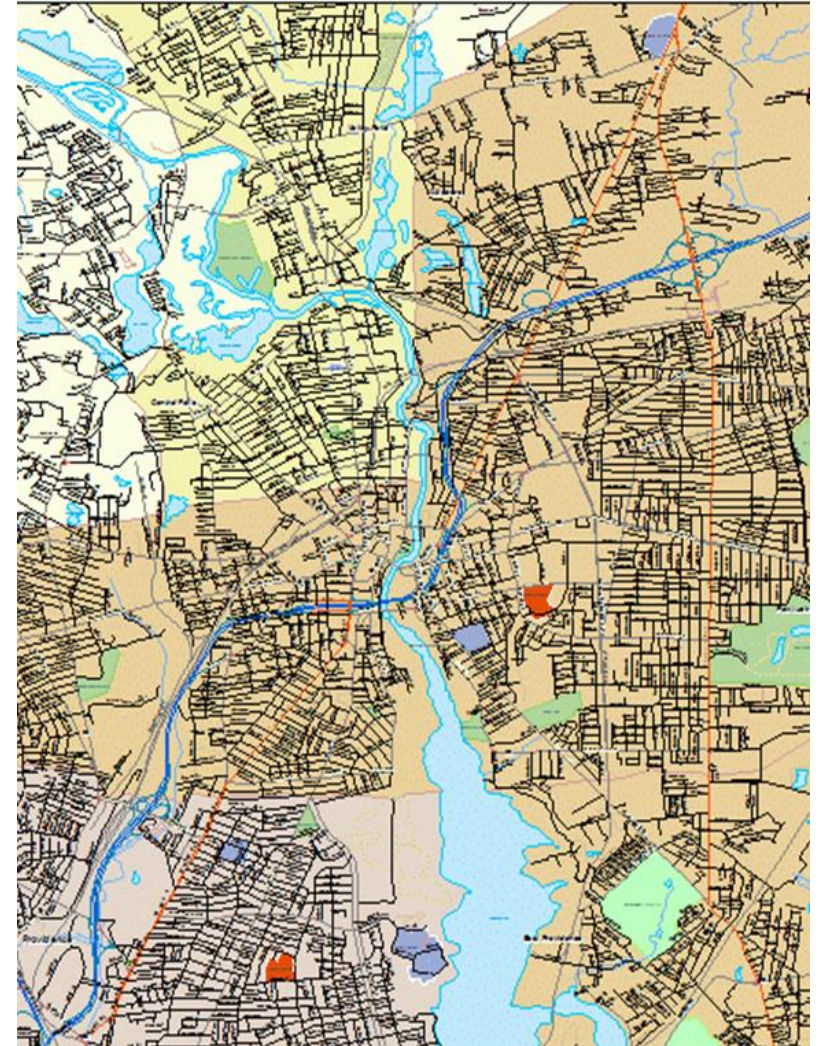
↑ odds of cognitive delay (aOR 1.62)¹

↑ odds of language delay (aOR 1.58)¹

↑ odds of behavioral challenges²
internalizing (aOR 1.96)
externalizing (aOR 1.71)

26% of high-risk neighborhoods infants use ED
vs 16% of low-risk neighborhoods.³

Encourage use of on-call MD telephone support.
Ensure EI and other supports are in place for HR families.

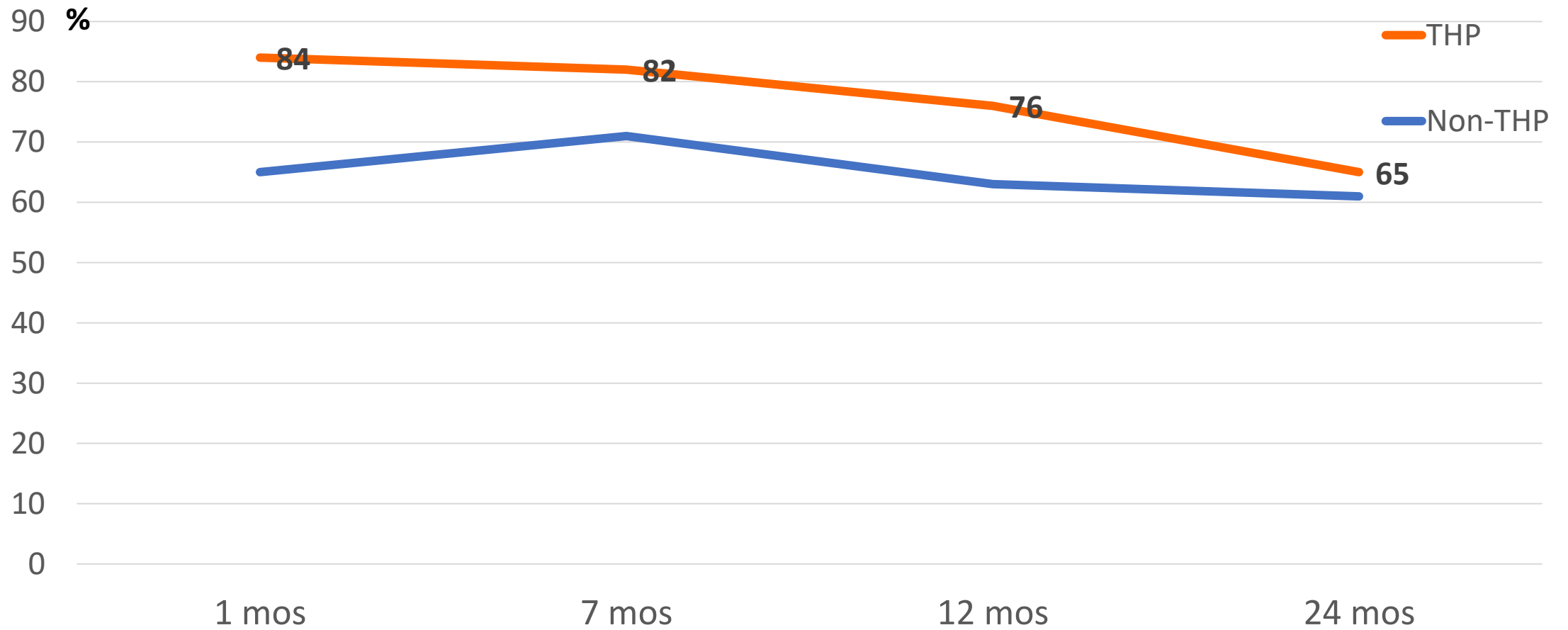


¹ Nwanne et al J Peds 2023, ² Nwanne et al Acta Peds 2024

³ Manickam et al, J Pediatr 2020;

FU Clinic EI Enrollment (2017-2025, < 34 wks)

Public Insurance (THP enrolled vs Non-THP)

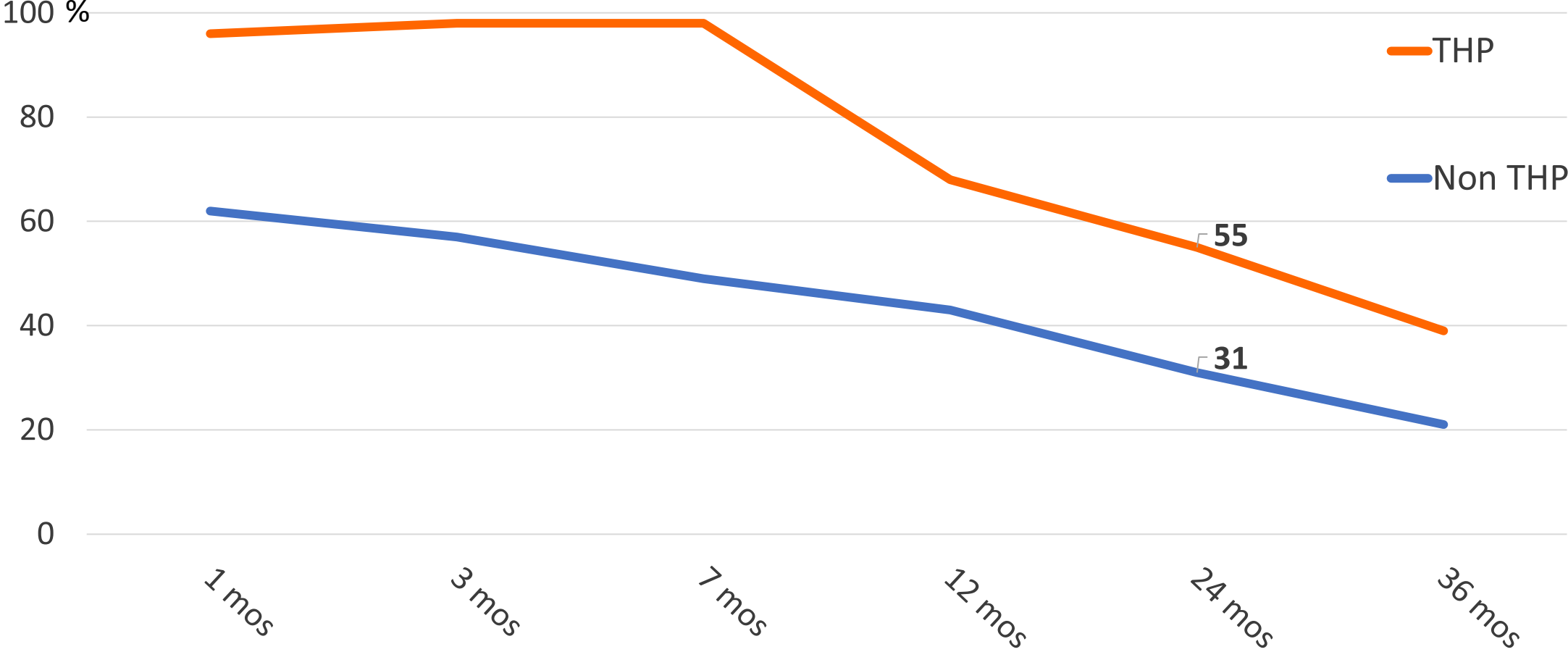


High Risk Infant FU Retention

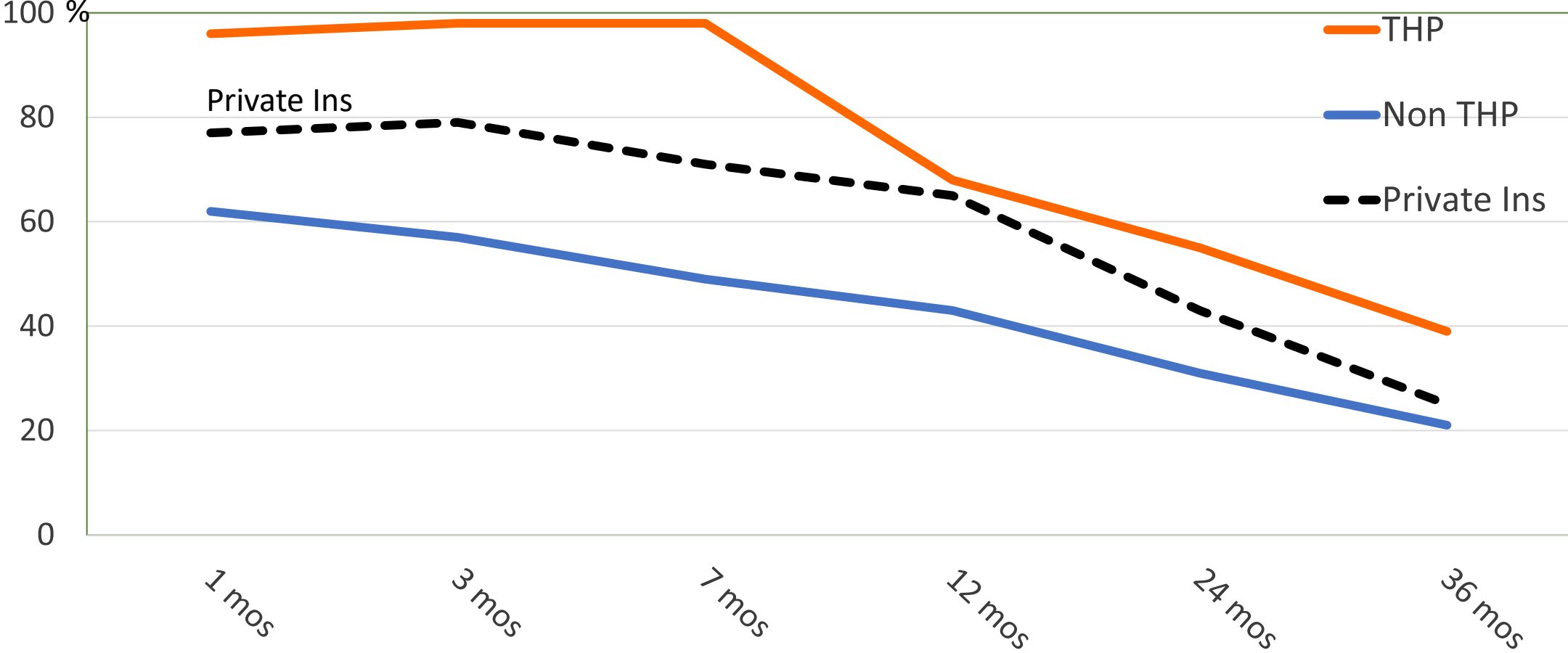
- Initial visits → suboptimal (~ 65-75%)
 - 2 yr rates variable
 - Funded research goal > 85-90 %
 - Unfunded collaboratives/networks
 - New England FU Network*
 - California Quality Care Collaborative*
 - Tremendous variation single sites
- } ~ 50%
- Low attendance
 - SES factors (low maternal education, public ins, non-Eng speaking, distance...)
 - Costs/co-pays
 - Continued attendance
 - Early engagement (completion V1, assigned provider)



FU Clinic Retention (2017-2025, < 34 wks) THP vs Non-THP



FU Clinic Retention (2017-2025, < 34 wks) THP vs Non-THP



The Importance of Families in the NICU



Importance of Sensory Input

- ~ 25 wks infants respond sound
- ~ 31 wks cochlea is mature
- ~ 32 wks pre-speech vocalizations and reciprocal parent-infant speech (“conversations”)

- When mother is visiting ↑ adult words, ↑ conversations
- Positive association between adult words and conversations
- Can teach parents how to “talk” & what is that benefit ?



RCT NICU Language Curriculum & 2 yr outcomes

Methods: N= 95 infants < 32 wks
reading vs health safety curriculum
measured AWC, and Conversational turns (CT).

Results:

At 36 wks CA

Reading Curriculum: ↑ AWC (rr 2.83; 1.89-4.24), ↑ CT (rr 2.54; 1.36-4.70)

2 yr outcomes

↑AWC & CT associated w/higher language score

Reading Curriculum: ↓ odds of language delay (aOR 0.20; 0.05-0.78)

This inexpensive, teachable model be introduced while in NICU, potentially “set the stage” for a language rich home environment ?.





Infant Neurobehavior

NICU Network Neurobehavioral Scale (NNNS)

~ 15 min exam, combines neurologic + behavior + stress signs

12 summary scores *attention, handling, regulation, arousal
excitability, lethargy, reflexes, tone, movement quality, stress*

- **Performed:** < 34 weeks GA, HIE
crib, nasal cannula (~ 32-33 wks)
- **Research**
Associations btwn abnormal NNNS
short term medical morbidities
2 - 5 yr behavior & developmental





Education Tool

- Behavior
 - Fussiness, crying -> steps on soothing
 - Interactions -> when to play vs rest
 - Subtle stress signs -> color change, spits
- Tone
 - Low vs high -> massage, strengthening
- Strengthen
 - Team communication
 - **Maternal confidence/self efficacy**
- Focus on the positives



Parental Involvement in the NICU

- Promote parental well being
- Improve maternal **“self-efficacy”**
- Enhance maternal-infant bond

- Support breast feeding/BM
 - ↓ morbidities & mortality
 - improving short & long term neurodevelopment & growth outcomes

- Kangaroo/skin-to-skin care
 - ↓ pain response, ↑ growth & temperature regulation
 - Improves BF, supports responsive caregiving/relationship

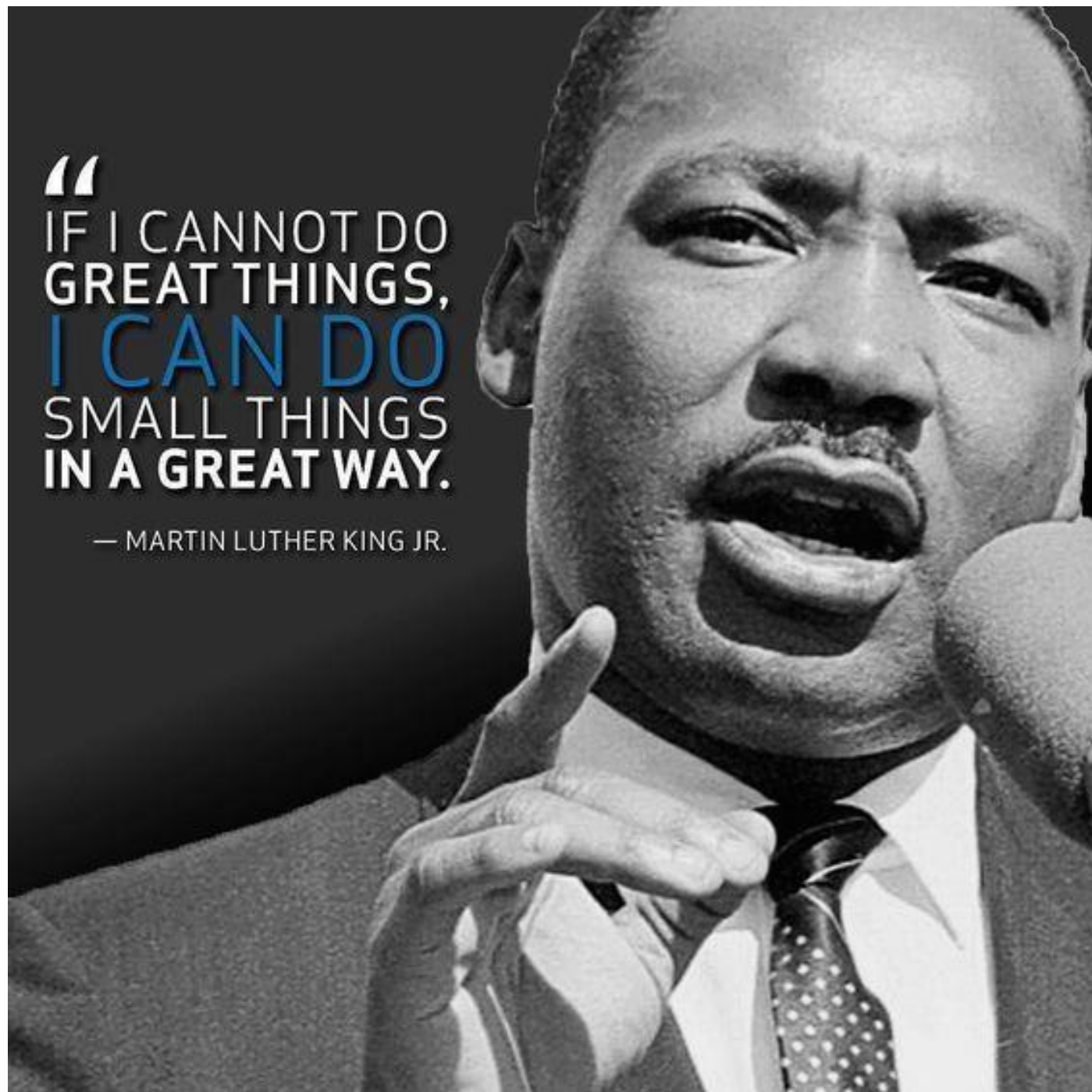


Summary

- The goal of a NICU FU Program recognize the changing needs of infants & families.
- Adverse outcomes are due to complex balance of biologic and environmental risks.
- Brain of PT infant is vulnerable, different mechanisms (& timing) of injury.
- The home environment is complex and multi-layered, therefore there is not one “magic bullet” to improve outcomes.
- Getting to know the “home environments” of your families will allow for tailored support.
- There are always opportunities (even if small) where you can provide enhanced support for families.

“
IF I CANNOT DO
GREAT THINGS,
I CAN DO
SMALL THINGS
IN A GREAT WAY.

— MARTIN LUTHER KING JR.



The Follow Up Team



Betty Vohr, MD

Elisabeth McGowan, MD

Julie Mayne, MD

Vita Lamberson, MD

Allison Gottlier, FNP

Meghan Sheehan, FNP

Vicki Watson, BS

Stephanie Moffat, BS

Heather Polochick, SW

Brigid Aguiar, SW

Richard Tucker, BS (statistician)

Tarsha Geoghegan

Val Martinez

Kelly Satti

Lordes Rios

Collaborators

Brown Center for Children at Risk

Brown School of Public Health

RI Dept of Health

RI Reach Out & Read, Early Intervention

NIH/NICHD Neonatal Research Network

Vermont Oxford Network



