Stronger Together: Enhancing Postnatal Outcomes Through Collaborative Care and Support

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Disclosures

I have no disclosures

Objectives

- **Understand and review the evidence on mental health challenges for parents of children at risk for developmental disorders in the post-NICU period**

- Compare types of social drivers of health and their impact on pre- and post-natal development in high-risk infants and their families

- Discuss the role of multidisciplinary providers and programs in providing screening and facilitating access to medical, legal, psychological health, and social supports for families in the first three years

Parental Behavioral Mental Health Conditions Post-NICU

- Post-traumatic stress is increased in mothers of infants admitted to the NICU
- Parental psychological distress may persist after a critical medical crisis passes & infants are discharged
- Rates of depression & anxiety are **2–5 times higher in mothers of infants born very preterm** throughout childhood
- 34% of mothers of very preterm infants have clinically elevated post-traumatic stress symptoms at 18–24 months

Ira Kantrowitz-Gordon, et al. Prolonged Distress of Parents After Early Preterm Birth, Journal of Obstetric, Gynecologic & Neonatal Nursing, Volume 45, Issue 2, 2016, Pages 196-209, ISSN 0884 2175, https://doi.org/10.1016/j.jogn.2015.12.004.

Parental Behavioral Mental Health Conditions Post-NICU

- Parental mental health problems can influence children's development, with one mechanism being through their influence on the parent-infant relationship
- Supporting parents of infants born preterm is important at a public health level
- Costs associated with mental health problems are estimated as one of the largest single sources of non-communicable health-related global economic burden

Karli Treyvaud, Alicia Spittle, Peter J. Anderson, Karel O'Brien, A multilayered approach is needed in the NICU to support parents after the preterm birth of their infant, Early Human Development, Volume 139, 2019, 104838, ISSN 0378-3782, https://doi.org/10.1016/j.earlhumdev.2019.104838.

Case 1

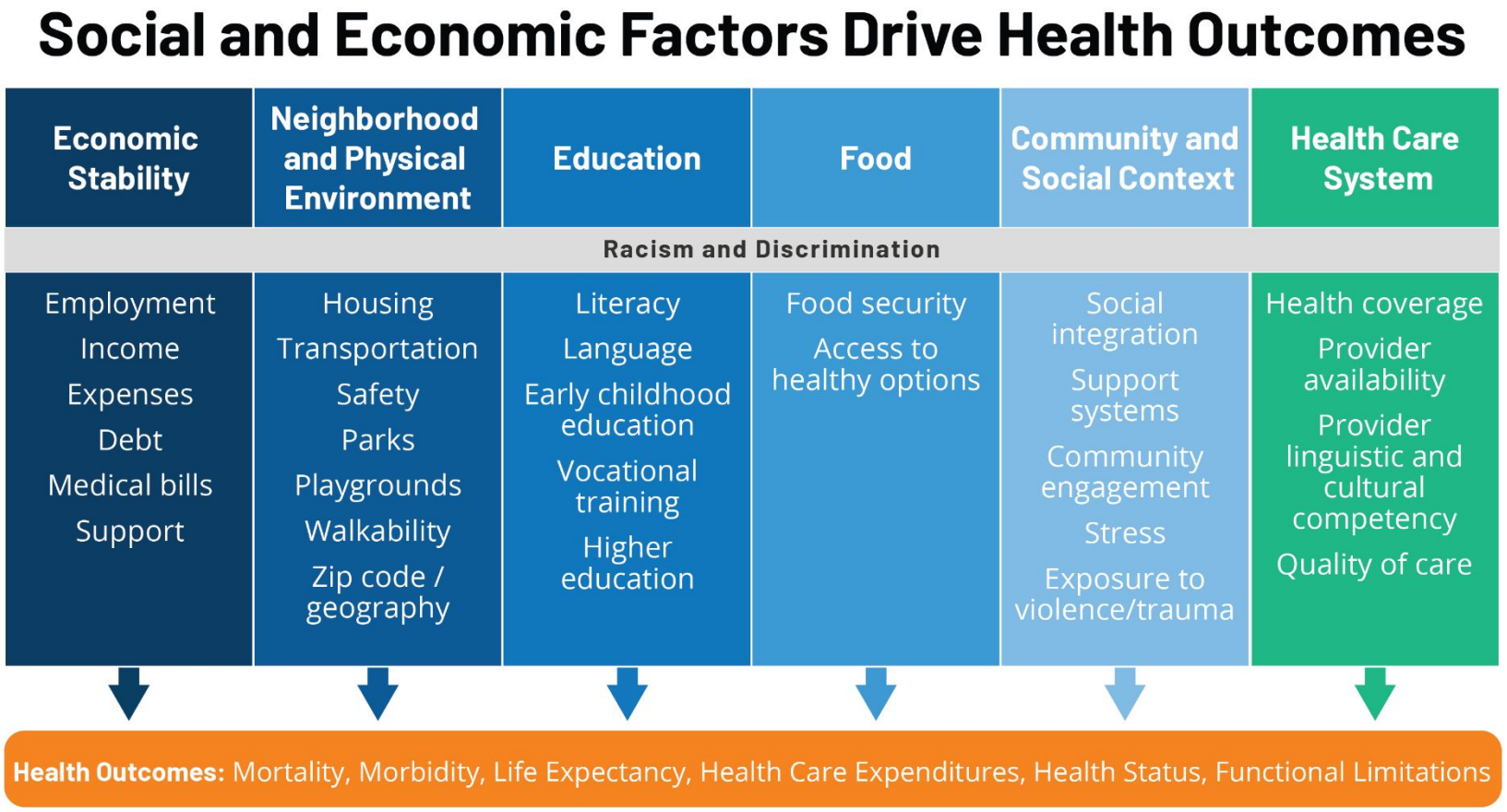
Objectives

- Understand and review the evidence on mental health challenges and social drivers of health for families of children at risk for developmental disorders in the post-NICU period

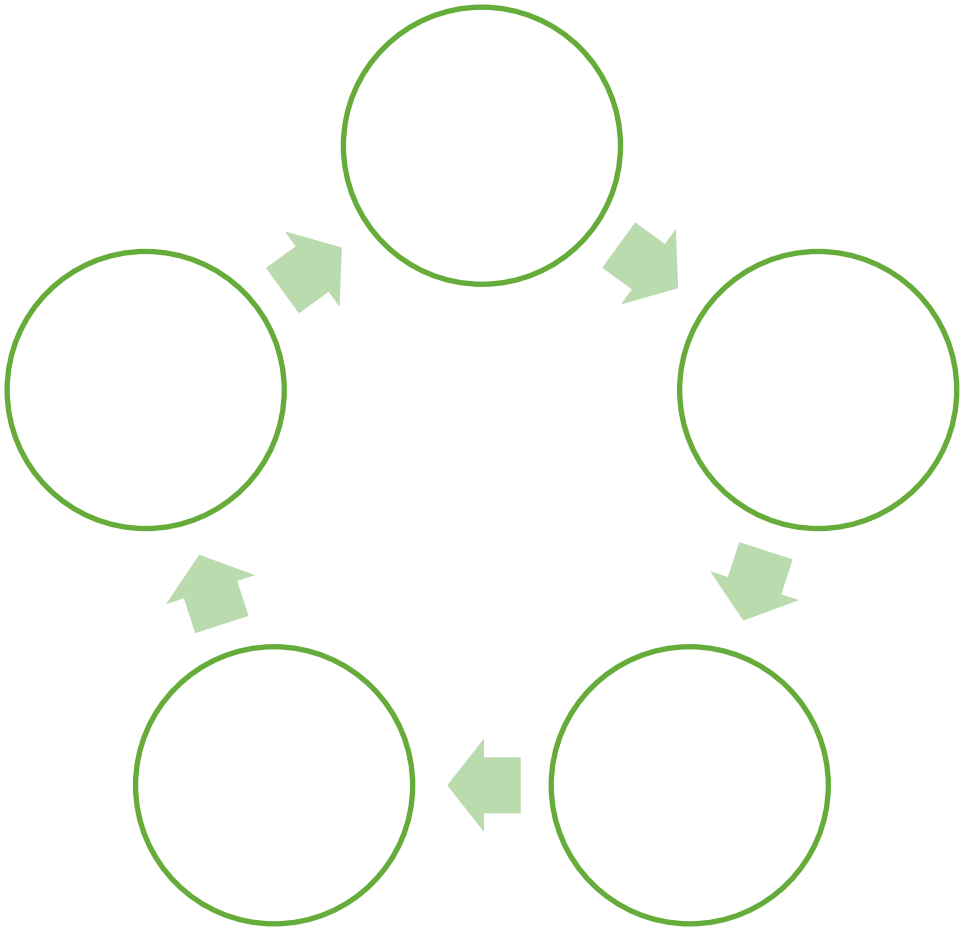
- **Compare types of social drivers of health and their impact on pre- and post-natal development in high-risk infants and their families**

- Discuss the role of multidisciplinary providers and programs in providing screening and facilitating access to medical, legal, psychological health, and social supports for families in the first three years

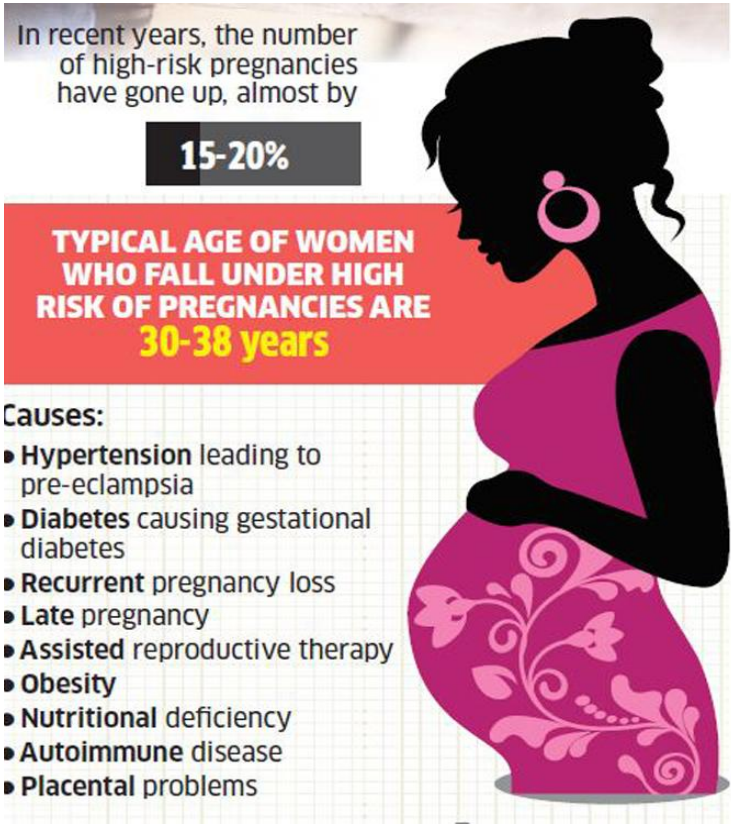
Social Drivers of Health



Impact of SDH



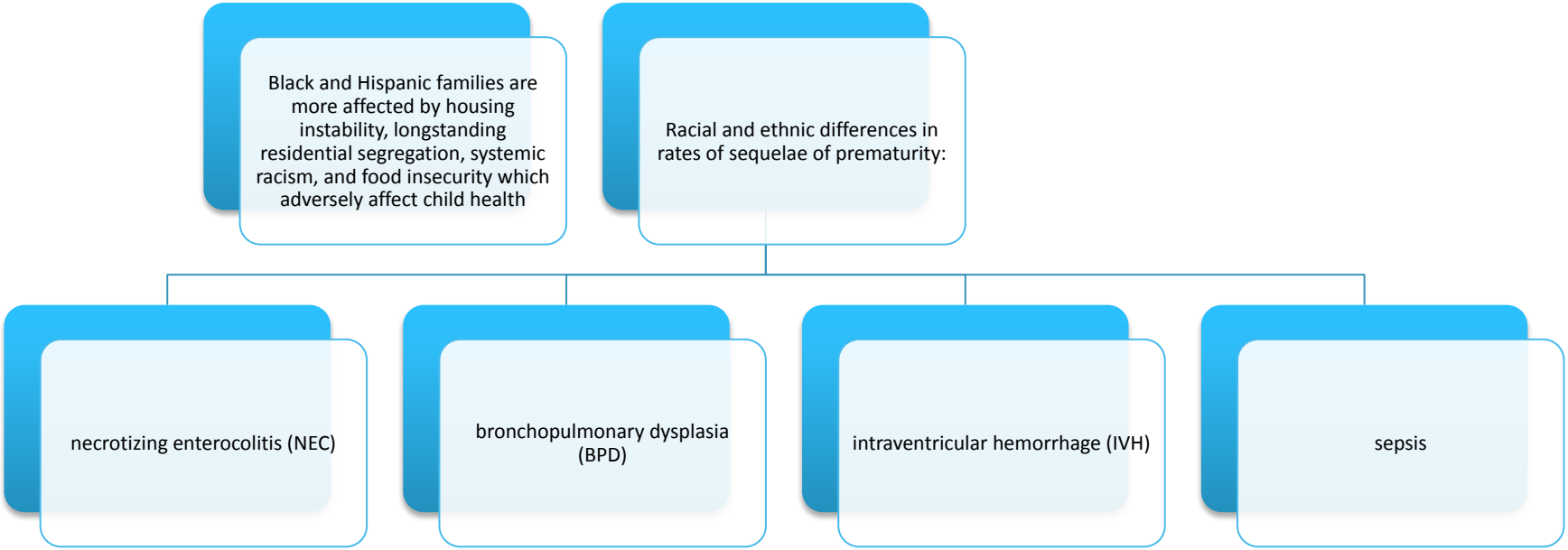
Impact of SDH: Preconception & Pregnancy Risks



- The majority of women (52%) have at least one preconception risk factor
- Nearly 20% have > 2 risk factors
- American Indian and Alaskan Native women had the highest rates of preconception risk factors (4-5)
  - drinking, smoking, diabetes, and mental distress
- Black women had the highest rates of obesity
- Hispanic women had the second-highest rate of diabetes

ET BureauLast Updated: Jul 03, 2018, 12:03 PM IST
Preterm Birth | Maternal and Infant Health | Reproductive Health | CDC
Howell 2018; Tucker 2007
ACOG Committee Opinion No. 649. 2015

Impact of SDH and Inequities Post-conception



Infants at High-Risk for developmental disabilities

1 in 6 children in the United States have a neurodevelopmental disability

Risk factors

- Boys, Non-Hispanic Whites & Non-Hispanic Blacks
- Rural & public health insurance

Increasing neurodevelopmental disabilities leads to increasing need for health & educational services

Unmet needs are associated with adverse impact for children with developmental disabilities and their families

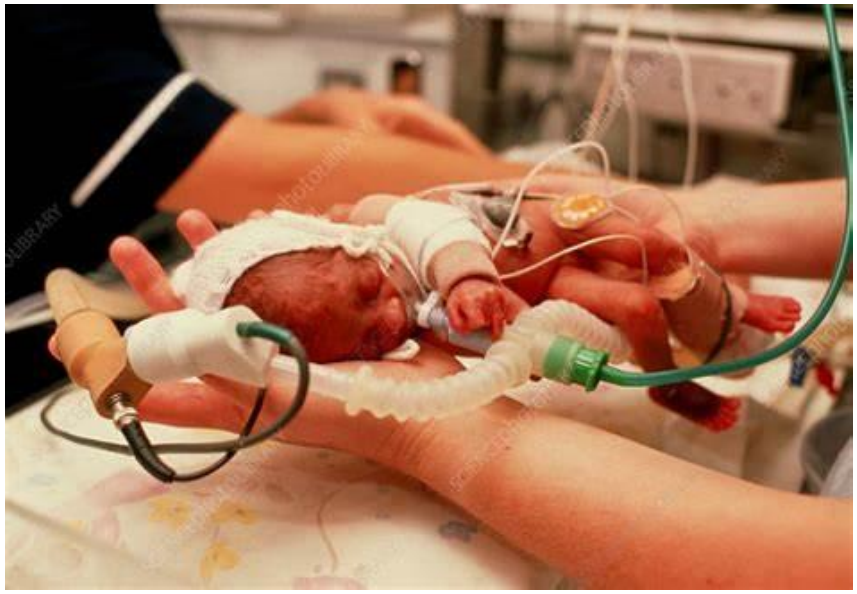
Zablotsky B 1989

Zablotsky B 2019

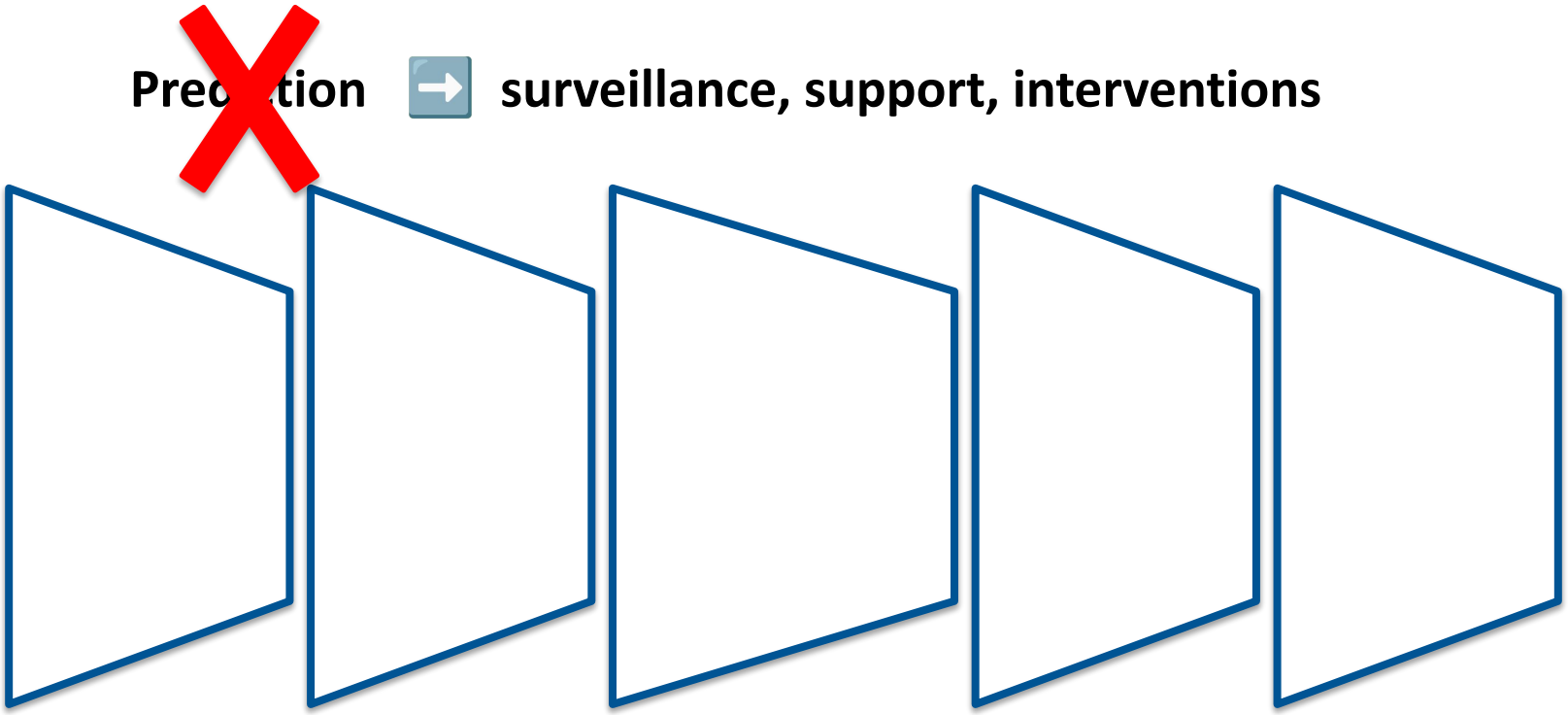
Which Infants are “High-Risk”?

- Preterm infant*
- Infant with special healthcare needs
- Dependence on technology
- Infant at risk because of family issues
- Infant with anticipated early death

- Congenital heart disease (CHD)
- Need for Extracorporeal Membrane Oxygenation (ECMO)
- Hypoxic Ischemic Encephalopathy (HIE)



High-Risk Infant Follow-Up Mission – Updated



Case 2

Social Drivers of Health

Objectives

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- **Discuss the role of multidisciplinary providers and programs in providing screening and facilitating access to medical, legal, psychological health, and social supports for families in the first three years**

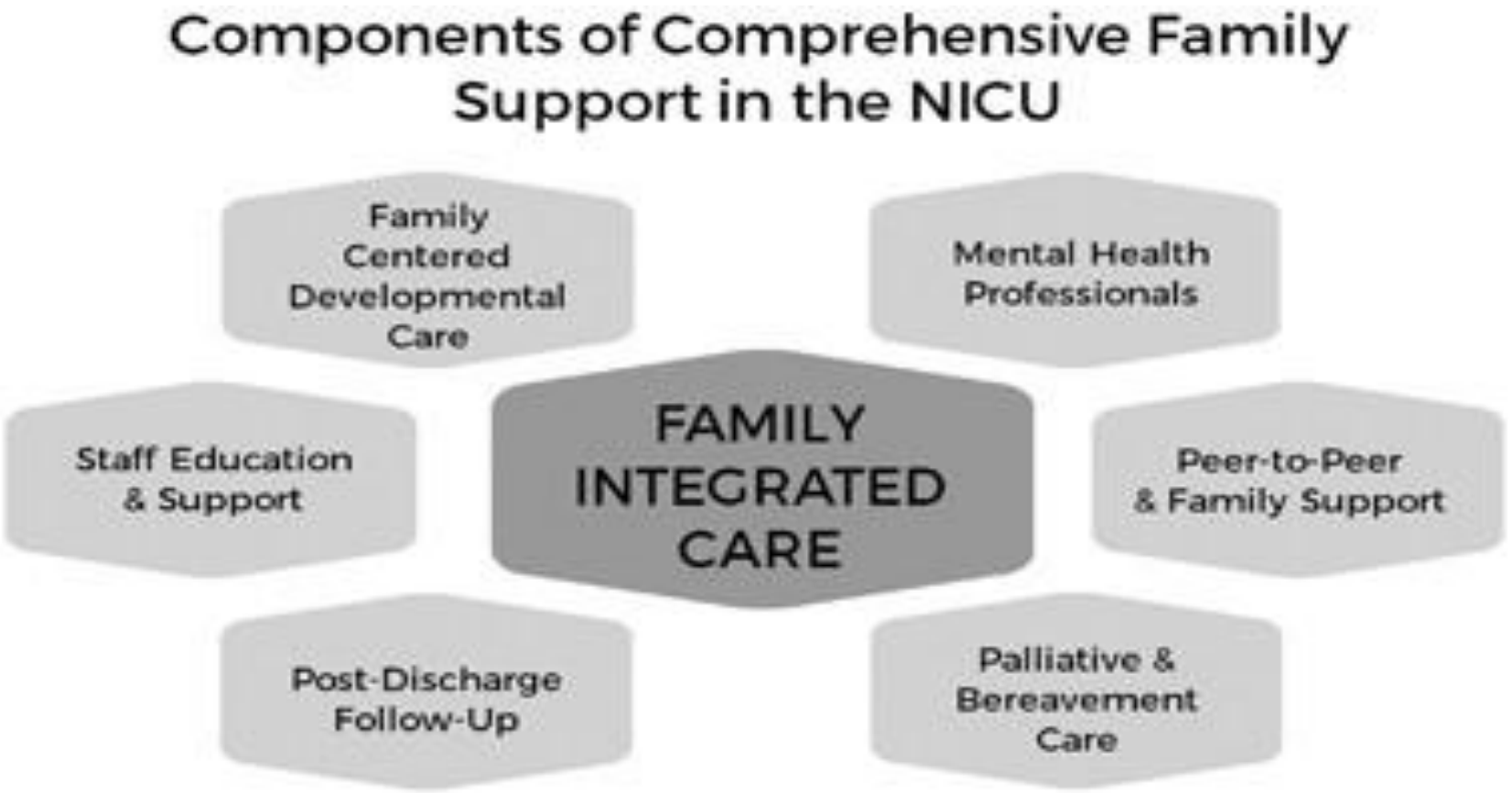
How do we work together to help?

Families with a high-risk infant have additional stressors

Prevention means breaking the cycle

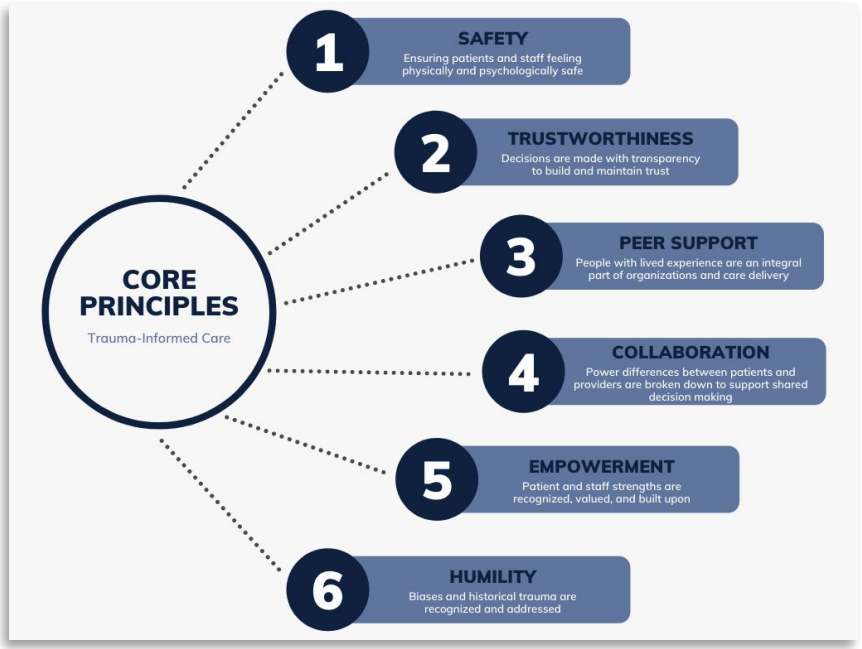
Change the thought process from an individual approach to a Team/Community approach

Multidisciplinary Approach to Care Inpatient



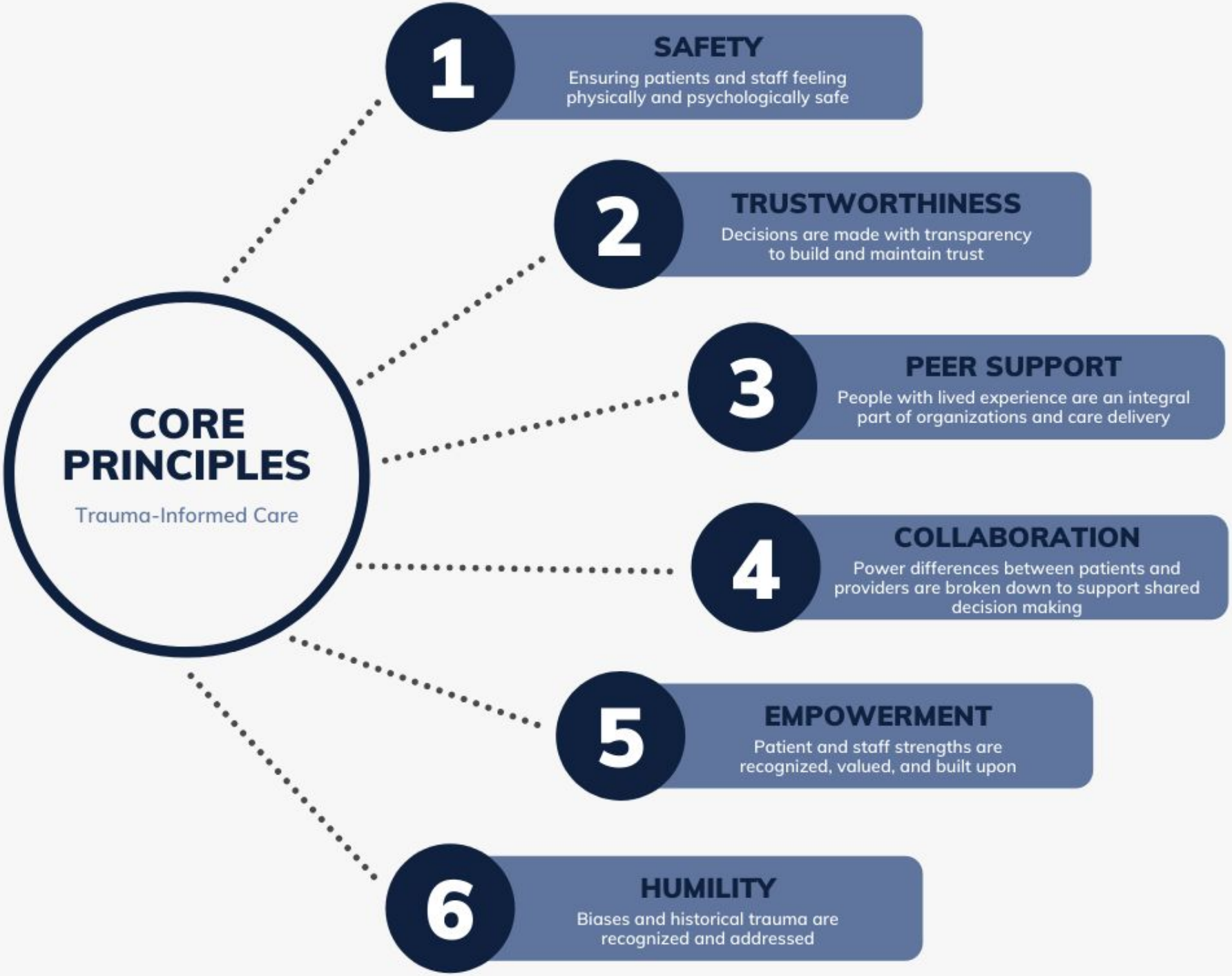
- Hall, S., Hynan, M., Phillips, R. *et al.* The neonatal intensive parenting unit: an introduction. *J Perinatol* **37**, 1259–1264 (2017). https://doi.org/10.1038/jp.2017.108

Trauma and Trauma-Informed Care (TIC)



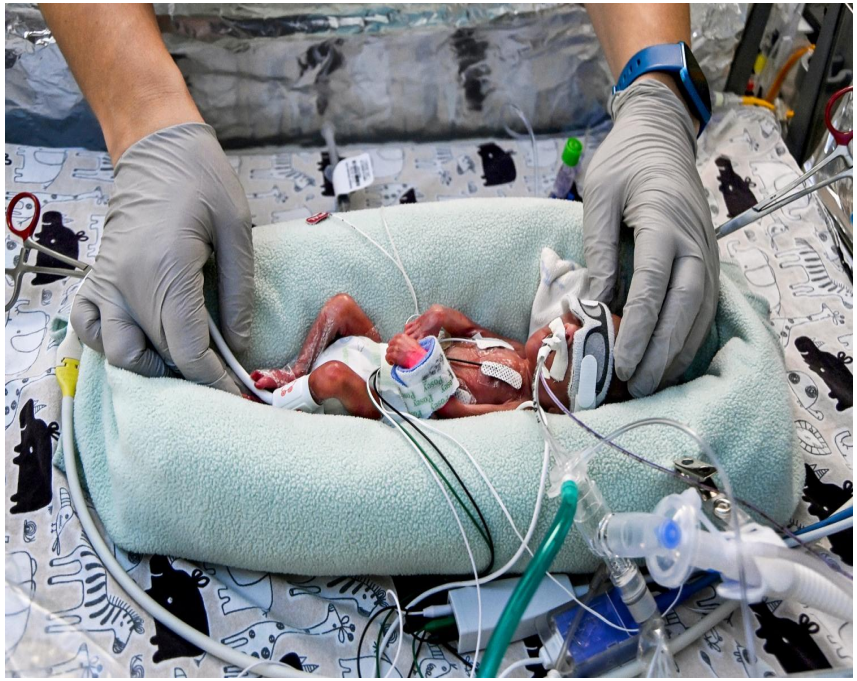
- Results from events or series of events that are physically and/or emotionally harmful or life-threatening and have long-lasting adverse effects
- TIC- approach within healthcare to integrate understanding of trauma into practice, policies, and environments
- Understand biological evidence of trauma without suggesting childhood adversity is destiny
  - Cortisol
  - Long-term effects
- Core Principles of TIC

- Heather Forkey, Moira Szilagyi, Erin T. Kelly, James Duffee, THE COUNCIL ON FOSTER CARE, ADOPTION, AND KINSHIP CARE, COUNCIL ON COMMUNITY PEDIATRICS, COUNCIL ON CHILD ABUSE AND NEGLECT, COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH; Trauma-Informed Care. *Pediatrics* August 2021; 148 (2): e2021052580. 10.1542/peds.2021-052580
- James Duffee, Moira Szilagyi, Heather Forkey, Erin T. Kelly; COUNCIL ON COMMUNITY PEDIATRICS, COUNCIL ON FOSTER CARE, ADOPTION, AND KINSHIP CARE, COUNCIL ON CHILD ABUSE AND NEGLECT, COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH, Trauma-Informed Care in Child Health Systems. *Pediatrics* August 2021; 148 (2): e2021052579. 10.1542/peds.2021-052579


CORE PRINCIPLES
Trauma-Informed Care
1
SAFETY
Ensuring patients and staff feeling physically and psychologically safe
2
TRUSTWORTHINESS
Decisions are made with transparency to build and maintain trust
3
PEER SUPPORT
People with lived experience are an integral part of organizations and care delivery
4
COLLABORATION
Power differences between patients and providers are broken down to support shared decision making
5
EMPOWERMENT
Patient and staff strengths are recognized, valued, and built upon
6
HUMILITY
Biases and historical trauma are recognized and addressed

How does trauma show up in NICU follow-up?

- PARENTS/CAREGIVERS
  - Primary and Secondary traumatic stress
  - Parenthood- hopes, dreams, and expectations
  - Sleep disturbances
  - Mental Health
  - Outside trauma sources
- INFANT/CHILD
  - Parental separation
  - Disrupted environment
  - Painful and stressful experiences
  - Immobilized
  - Future risks



Developmental Progress Clinic Screening

- Edinburgh Post-Partum Depression Scale
- PHQ-2 depression questionnaire
- SDH questionnaire/Family Resource Survey
- PTSD 5
- ACEs Philadelphia version*

Adverse Childhood Experiences (ACEs)

ACE Version	ACE Type
Kaiser & Philadelphia	Lack of food, clothing, home, protection
	Sexual Abuse
	Jail
	Mental Abuse
	Physical Abuse
	Violent Harm
	Drugs
	Mental Illness
	Feelings of being unprotected
	Divorce
Philadelphia only	Witness violence
	Experience in Foster Care
	Discrimination

Social Determinants of Health in Cerebral Palsy

No group differences in frequency unmet social or mental health needs

In the entire caregiver cohort (n = 194), 21% met the initial screening criteria for depressive symptoms.

The initial screening for PTSD symptoms was positive for 20% of caregivers

>/= 4 ACEs were reported by 13% of parents

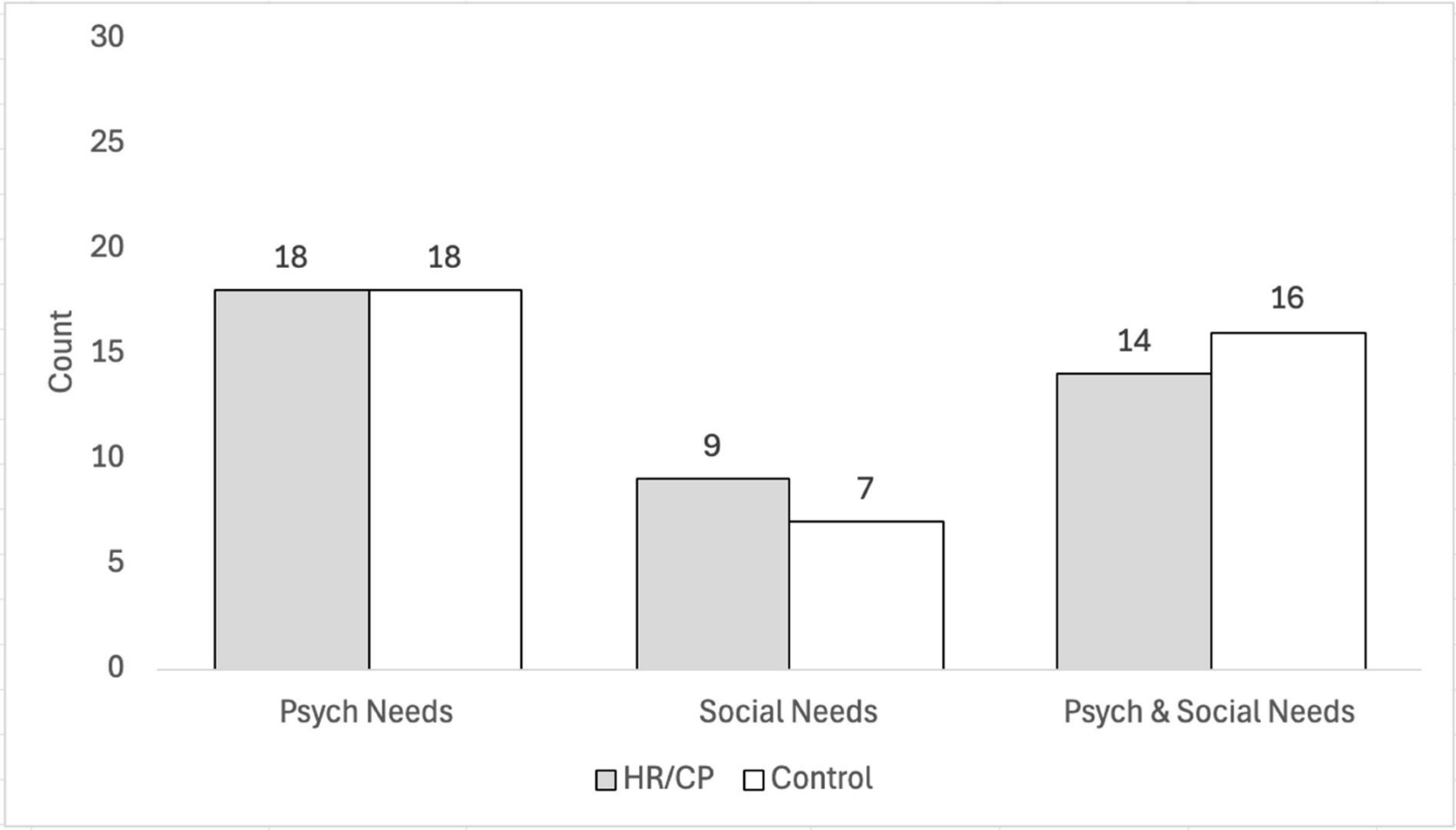
50% of caregivers reported experiencing discrimination

68.4% had felt unprotected (feeling unsupported, unloved, and/or unprotected)

75% had lived with a family member experiencing mental illness

Kendrick-Allwood SR, Murphy MM, Shin KS, Minaz A, Walker LK, Maitre NL. Social Determinants of Health in Cerebral Palsy. *Journal of Clinical Medicine*. 2024; 13(23):7081. https://doi.org/10.3390/jcm13237081

Frequency of Co-occurring Psychological Factors with Social Needs by Group



Interventions for Families

- Establish an emotionally safe environment
- Active listening
- Screen for maternal/paternal health and provide resources
- Support groups
- Facilitation of infant/family bond
- Staff Training

Interventions for Patients

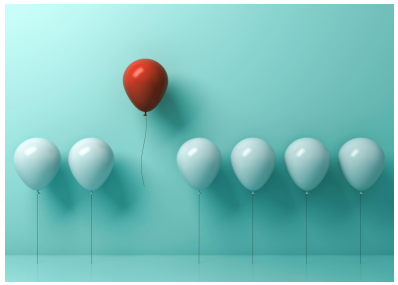
- Gentle handling
- Soft lighting/high-pitched sounds
- Listen to the baby's cues
- Reducing pain
- Involve the family
- Be flexible
- Sing/rhythmic sounds

Interventions for Providers

- Resilience promotion
- Investigate one's own story and trauma
- Provide screening, support, and resources for families
- Advocate for families

Policies, protocols, and practices don’t transform experiences; people do



Resources provided

- Social Security Income (SSI):
  - 1250 gms or Less
  - 31+ days hospital
  - Chronic Health Issues (Trach, Cerebral Palsy, Autism, etc.)
  - Stipend and SSI Medicaid (Federal)
  - Parents' Income will be assessed

- Katie Beckett Waiver:
  - Patient meets medical eligibility
  - Parents are over Income for SSI
  - Application Process (Psychological Test required)
  - No financial benefit

- Advocacy:
  - Health Law Partnership (HeLP)*
  - Healthy Grandparents
  - Cerebral Palsy Foundation

- Parent Group

Find Help GA:	•Resource portal (Zip Code needed) •Free/low-cost community resources (Food, Housing, Health Care and Job Training) •Open to All
Community Resource List 1:	•Utilities, Food, Housing, Childcare, Education, and Job Training •Sheltering Arms/Easter Seals (Childcare)
Community Resource List 2:	•Mental Health: Counseling/Therapy
Community Resource List 3:	•Housing (Silverton Foundation, Section 8)

Collaborations and Community Affiliates

- Marcus Autism Center
- Emory School of Medicine Psychology & Psychiatry - Neuropsychology
- Georgia State University
- Cerebral Palsy Foundation
- Children's Rehabilitation Services
- HeLP*
- GA Pines
- BEGIN
- Lekotek
- FOCUS
- Miss Gussies Place
- SPRITE clinic
- Community Pediatricians, subspecialists and NICU's
- Parent Group for NICU graduates
  - Katie Beckett, Babies Can't Wait, School Psychologists, etc.
  - Most importantly parents/caregivers

The Health Law Partnership (HeLP)

- HeLP, a medical legal partnership
  - Lawyers – Atlanta Legal Aid
  - Law Students – Georgia State Law School
  - Physicians – Peds Institute/Emory and Morehouse Schools of Medicine
  - Medical Students & Residents – Emory and Morehouse Schools of Medicine

HeLP
HEALTH LAW PARTNERSHIP

HeLP in children with Neurodevelopmental Disabilities (NDD)

651 caregivers/clients, 724 dependents receiving HeLP services

Caregivers' characteristics:

- 59.1% Black/African American
- 87.5% female
- 42.7% single
- 31.2 % employed
- Mean age 35.8 years (±13.2)
- Mean household size 4.2 persons (±1.8)

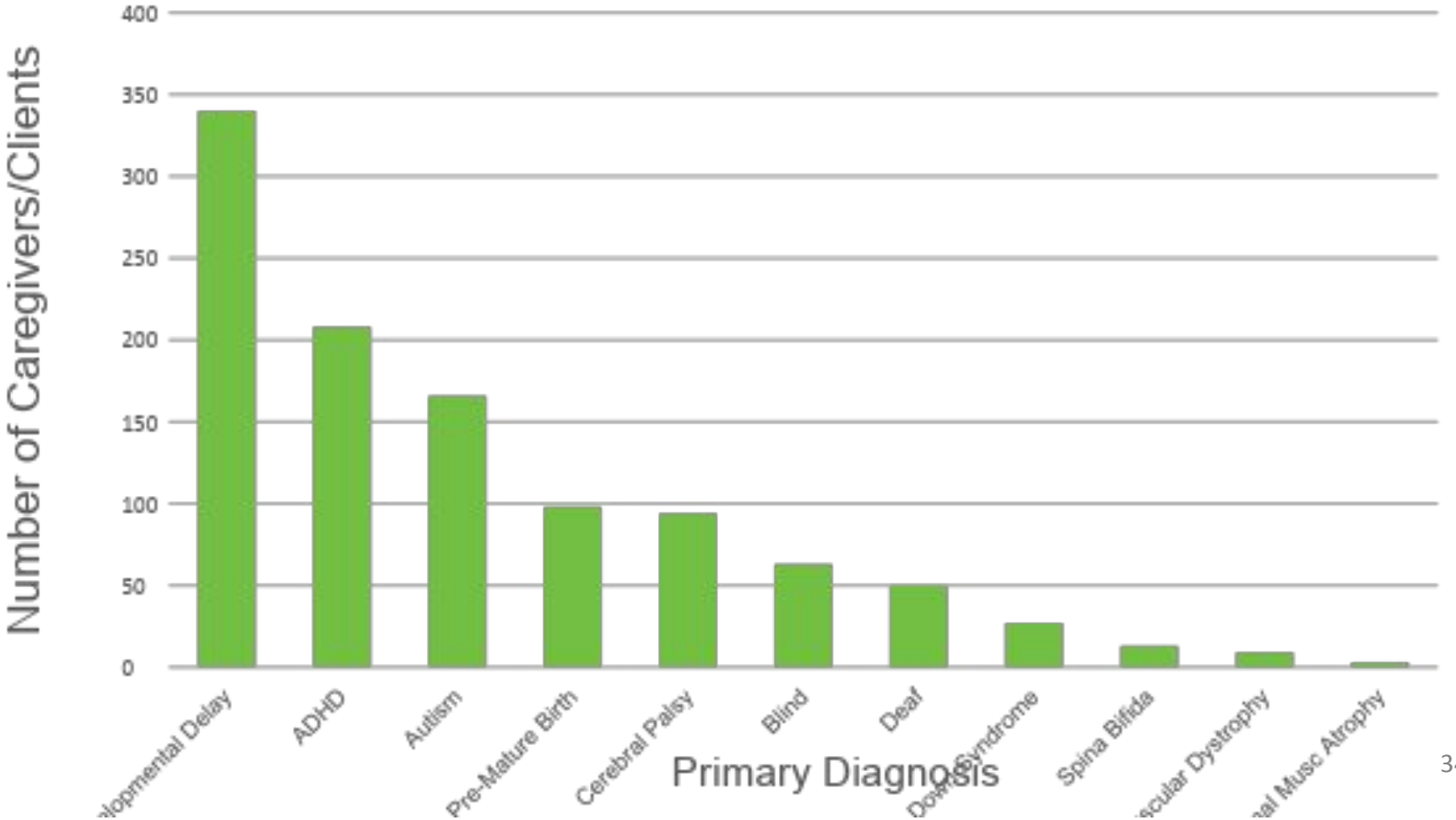
Children:

- 62.4% males
- 56.7 % had an individual education plan (IEP)
- 7.5 % had a 504 plan

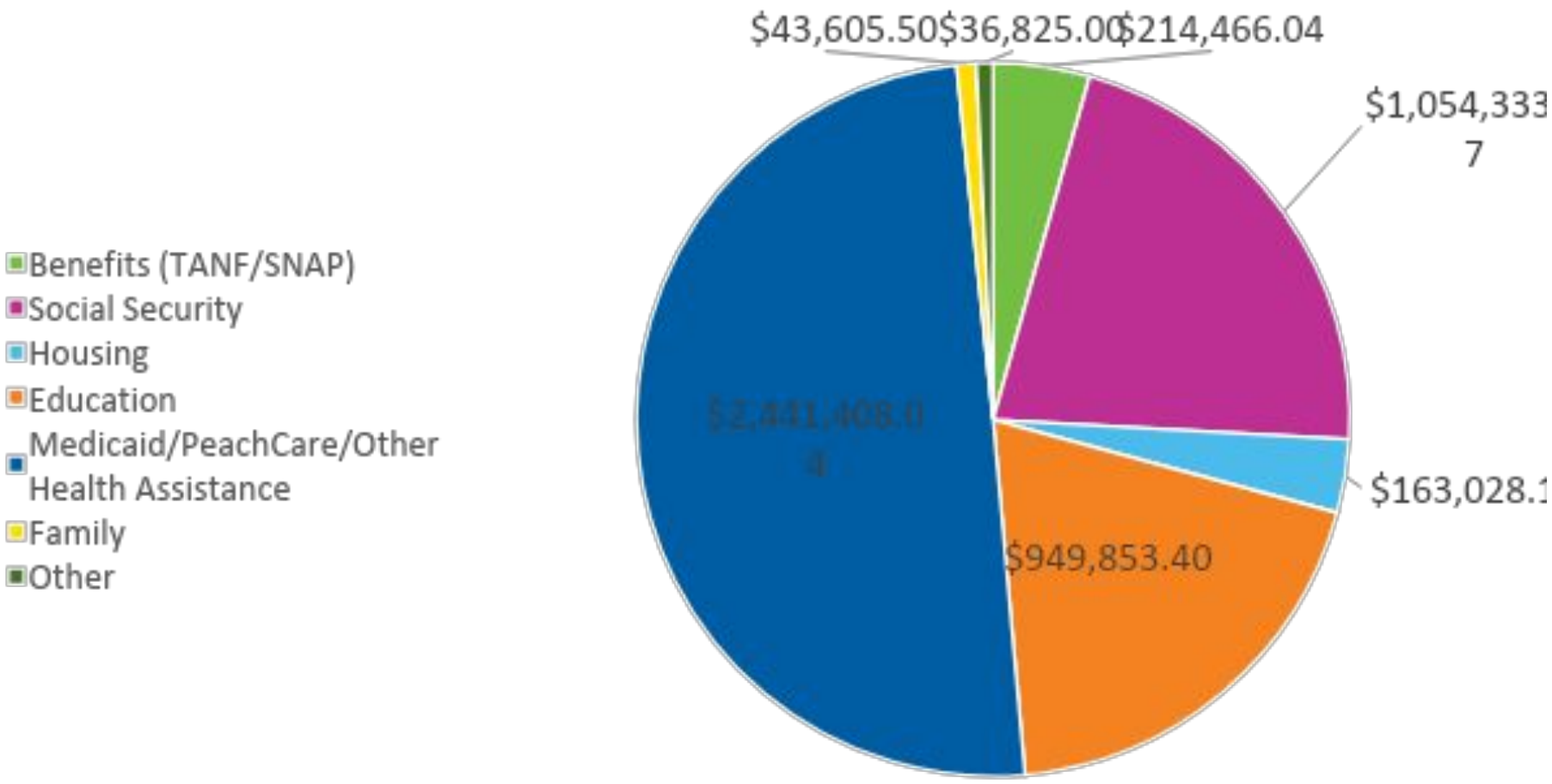
Kendrick 2021

Diagnoses of children served

N= 1071



Annual Dollar Amount Gained by Case Types



HeLP in Children with NDD

- Improved access to health care and education resources
- Financial cost savings to families
- Cost savings to the health care system by securing entitlement benefits (Medicaid, SCHIP, SSI)
  - For children with neuro-developmental disabilities
  - may otherwise be attributed to indigent or charity care
- Access to entitled benefits and resources results in short- and long-term cost savings to both families and systems

HeLP
HEALTH LAW PARTNERSHIP

Summary

What we know?

- SDH, inequities, and disparities negatively impact health outcomes will be more pronounced in children with neurodevelopmental disorders

Who are those in need?

- Our most vulnerable populations – infants at risk for neurodevelopmental disabilities

Why we need HRIF?

- Surveillance, support, and interventions (early)

Why we need community engagement?

- To address social drivers of health, health disparities and inequity - JUSTICE

How can we help?

- Engage caregivers, primary care providers, & community partners
- Collaborate with interdisciplinary partners
- Advocate with state and federal legislators on behalf of our neurodevelopmentally challenged children and their families

Questions?

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