UNIVERSITY of WASHINGTON

The Intersection of Intellectual and Developmental Disability (I/DD) and Trauma

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Today's Talk

- Defining I/DD and trauma
- Adverse childhood experiences and development
- Disproportionate rates of trauma among people with I/DD
- Common scenarios and barriers
- Adult Neurodevelopmental Wellness (ANeW) project

Reminders

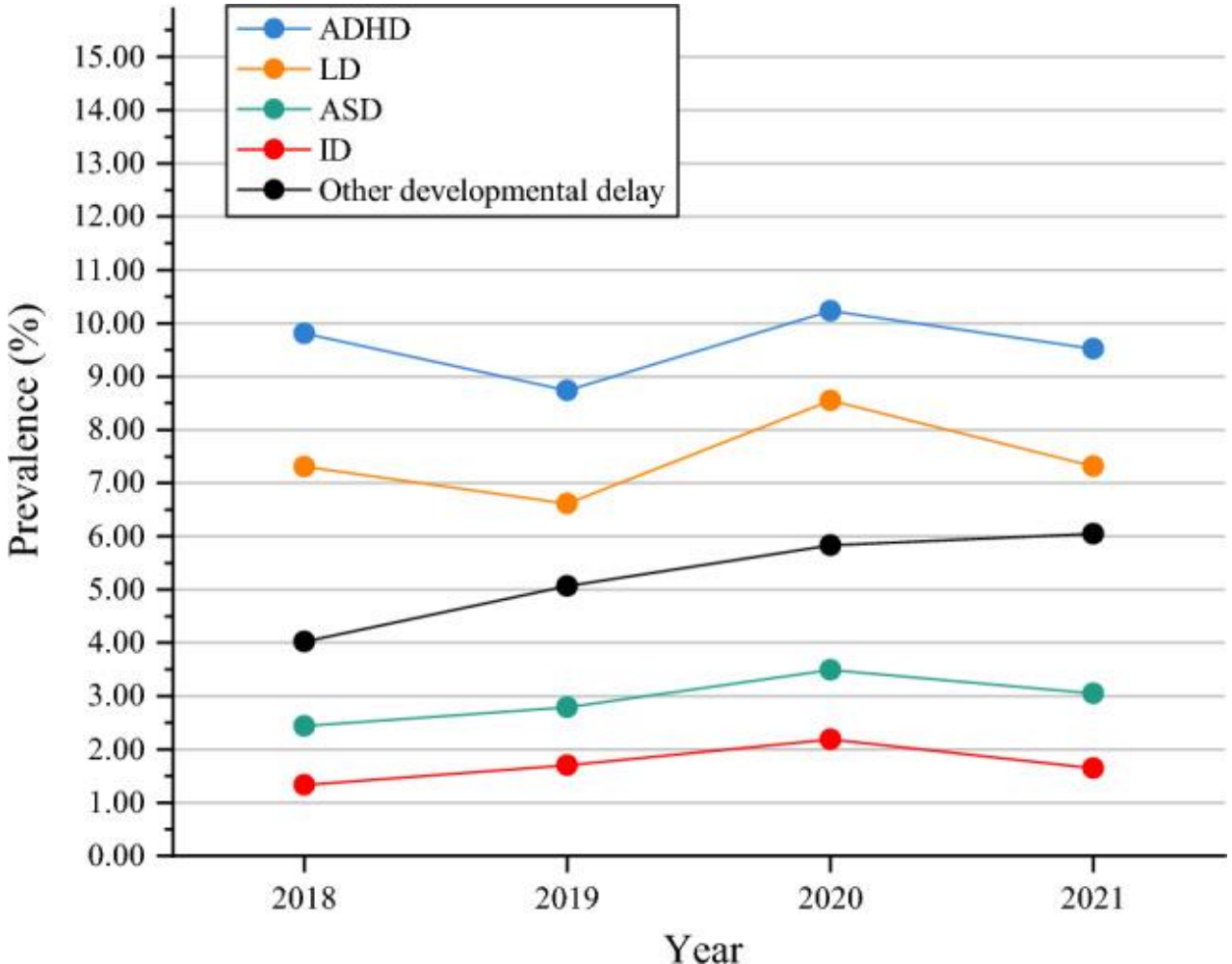
- As someone who does not identify as disabled, I cannot truly understand the experiences of individuals with disabilities. I remind you all to listen to, befriend and support disabled folks regularly to best learn about their experiences and advocate effectively.
- This presentation involves sensitive topics that may provoke difficult thoughts and emotions. I encourage you to care for yourself and step away if needed.

What is Intellectual and Developmental Disability (I/DD)?

- Differences in physical, intellectual, social and/or emotional development
- Typically begin during childhood
- Typically lifelong
- Intellectual disability: difference specific to reasoning, problem solving and adaptive skills
- Developmental disability: broader category of lifelong challenges including intellectual, physical, social and/or emotional differences
  - Examples: autism spectrum disorder, cerebral palsy, learning disabilities

I/DD is common!

~1 in 6 children have a developmental disability.



What causes I/DD?

Complex interplay of many factors:

- GENETICS
- Epigenetics (factors that modify the genome)
- Prenatal environment/exposures
  - Illness, substance use, stress, poor nutrition
- Childhood environment/traumatic experiences early in life, especially when chronic
- Adult causes of intellectual disability: traumatic brain injury, dementia

What is Trauma?

- Frightening, dangerous or violent event(s) that poses a threat to life or bodily integrity
  - Includes witnessing traumatic event(s) or learning they happened to loved one
  - Often initiates strong emotions and physical reactions that persist long after event(s)
- May cause long-lasting negative effects on physical, emotional, social and spiritual well-being and function
- Associated with many chronic physical and mental health conditions
- Effects can be inheritable through generations.

Adverse Childhood Experiences (ACEs)

Original study (1998)**:**

- **Abuse** (emotional, physical, sexual)
- **Neglect** (emotional, physical)
- **Family circumstances:**
  - **Parental separation or divorce**
  - **Mental illness**
  - **Substance abuse**
  - **Domestic violence**
  - **Incarceration of family member**

Expanding on original study (2015)**:**

- **Poverty**
- **Exposure to community violence**
- **Bullying**
- **Racial discrimination**
- **Foster care**
- **Separation from parents**

Additional categories proposed:

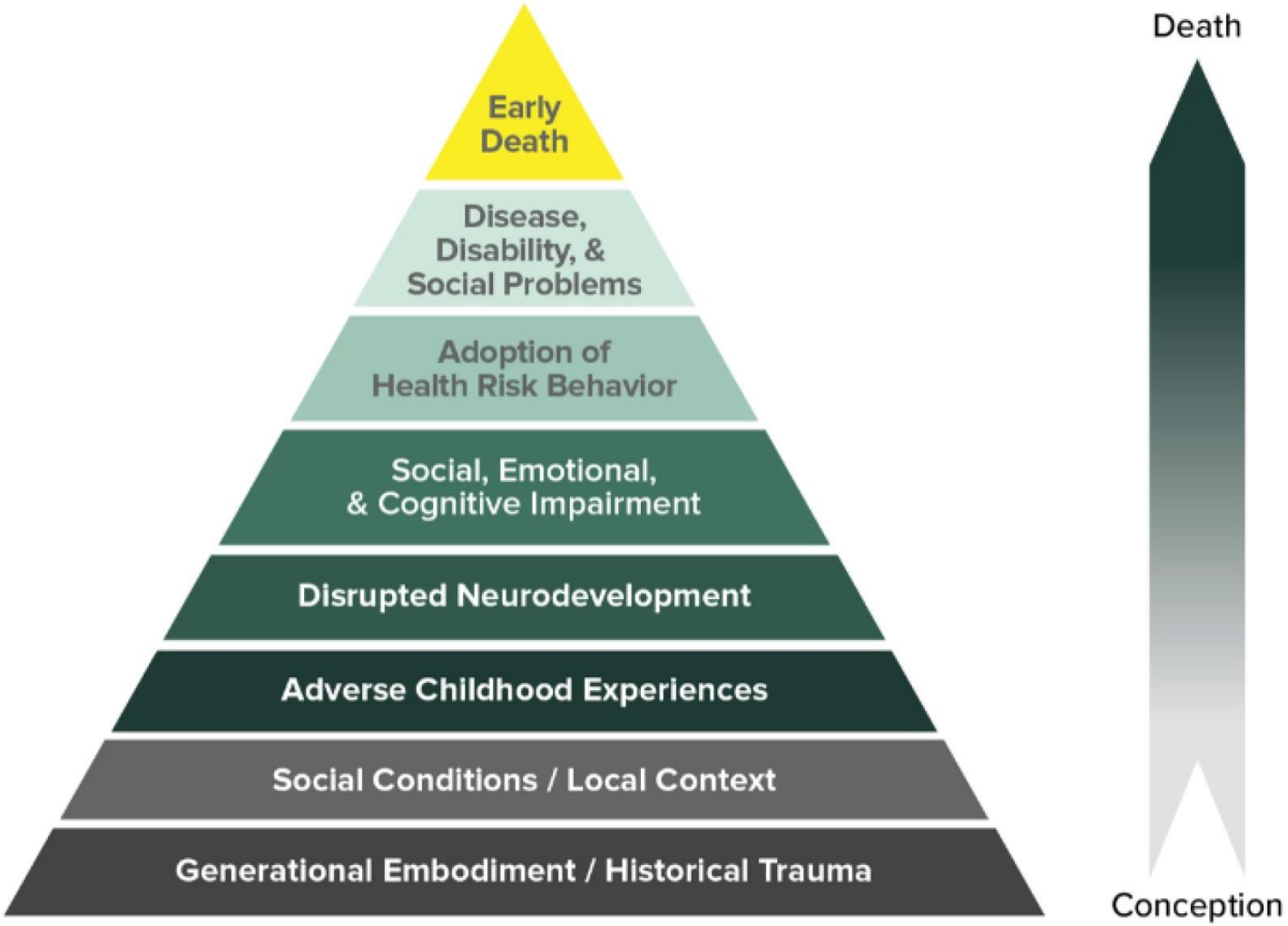
- Natural disasters
- Accidents
- War

Adverse Childhood Experiences (ACEs)

Per 2021 data:

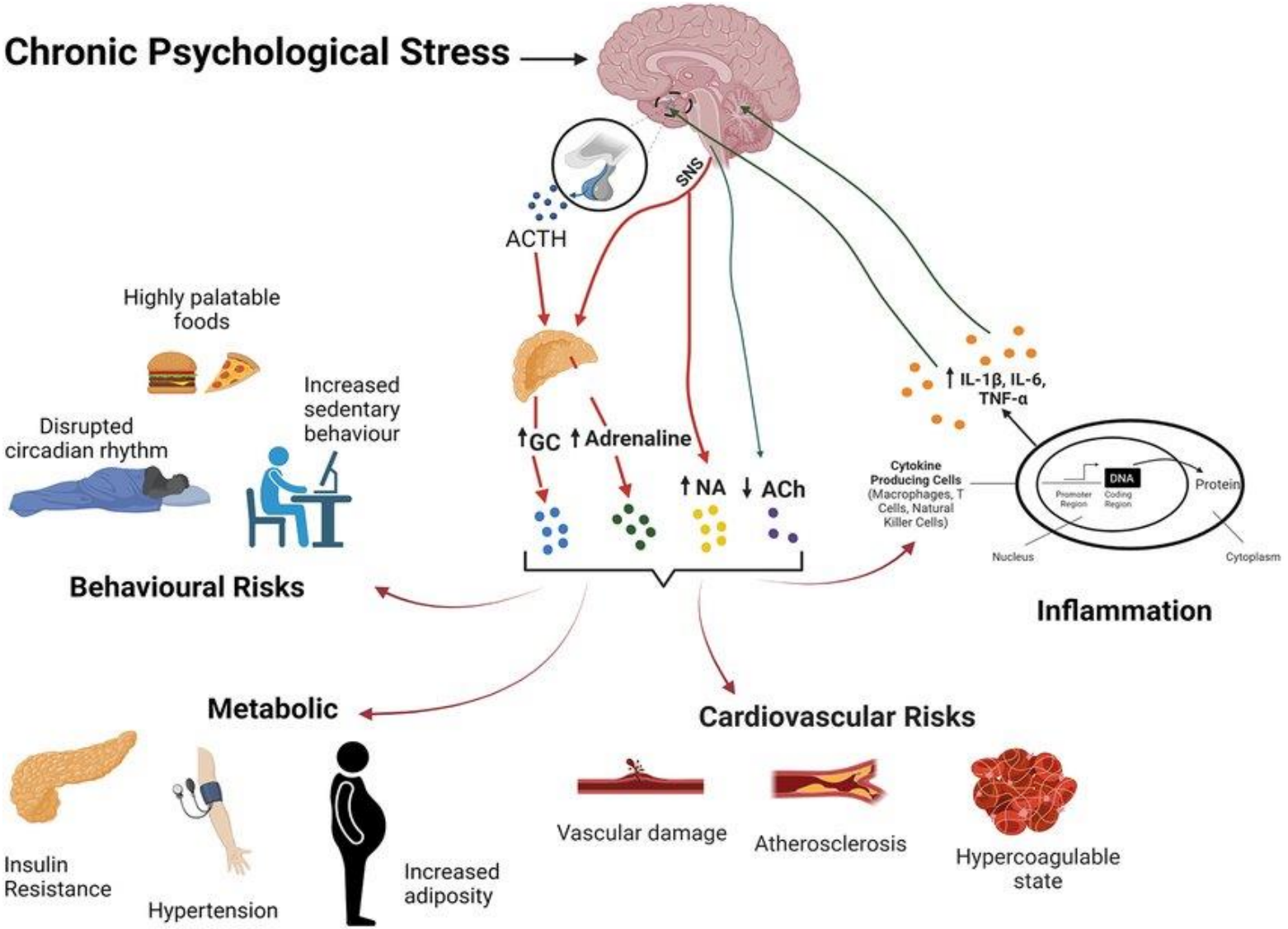
- **60.9%** of adults reported **1+** ACE
- **15.6%** (nearly 1 in 6) reported **4+** ACEs
- ACEs contribute to a variety of physical, mental and developmental health issues.
  - Generally dose-dependent and genetically-driven
  - 4+ ACEs: 4-12x prevalence of physical and mental health issues

Adverse Childhood Experiences (ACEs)



Mechanism by which Adverse Childhood Experiences Influence Health and Well-being Throughout the Lifespan

How do ACEs affect child development?



How do ACEs affect child development?

Chronic activation of stress response

↓

Dysregulated stress response systems

↓

Chronically dysregulated hormones + inflammation

↓

Disruption of brain architecture, advanced aging, heritable changes to DNA

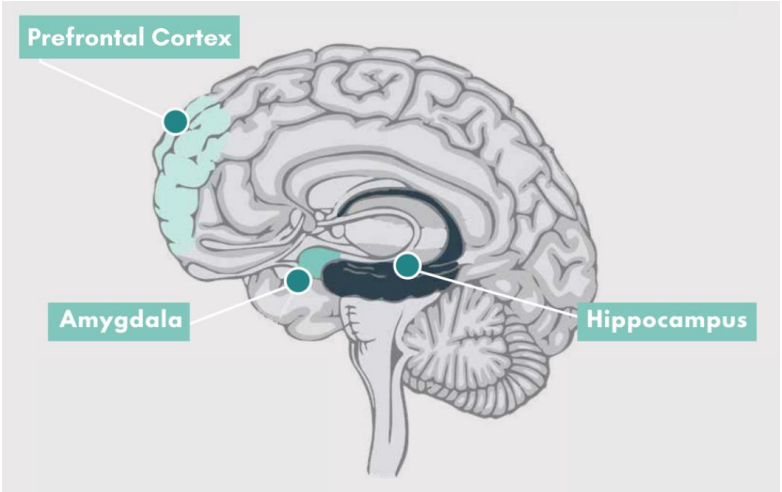
↓

Neurodevelopmental differences

Disruption of Brain Architecture

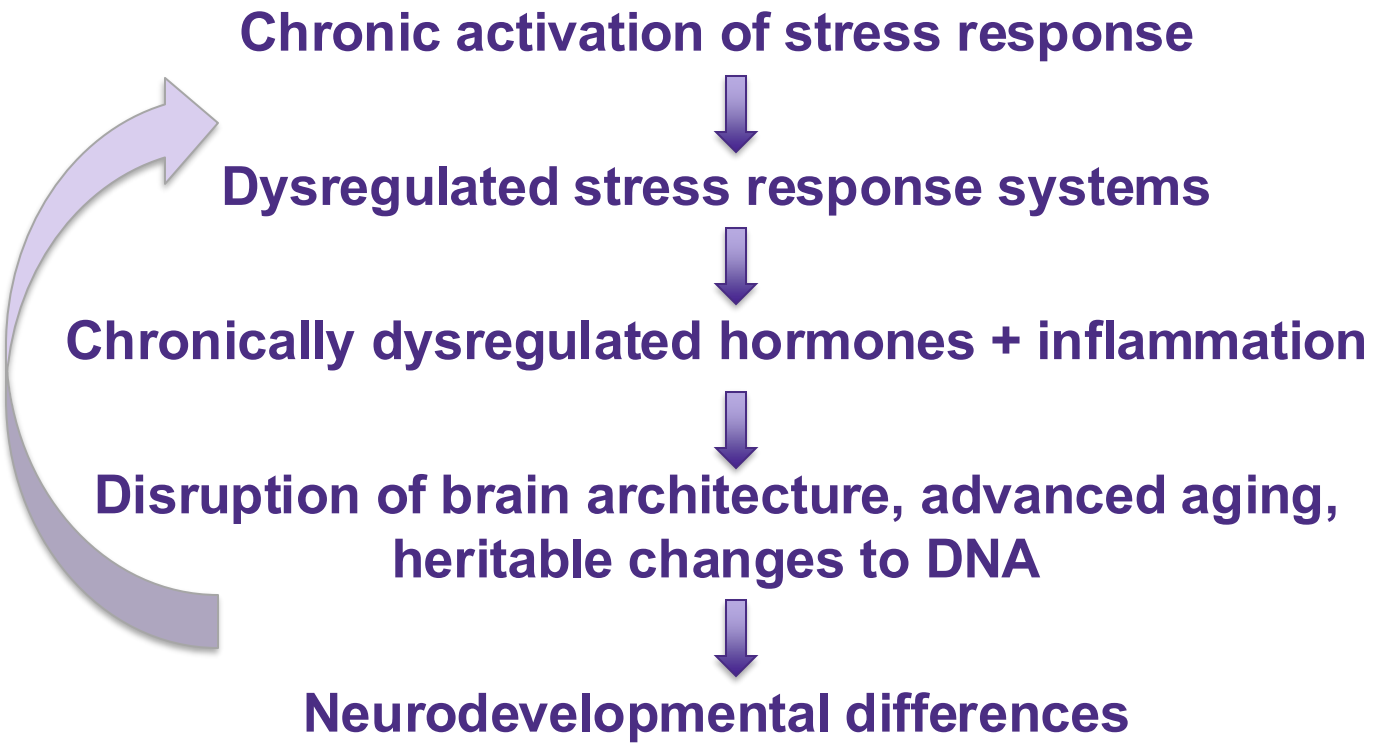
Very complex but commonly involve:

- **Amygdala** (emotions, especially fear and anxiety)
  - Hyperactivity
- **Hippocampus** (memory)
  - Reduced volume
- **Pre-frontal cortex** (executive function)
  - Reduced volume, impaired recruitment (decoupling with amygdala)



How do ACEs affect child development?

Indirect effects: increased risk-taking behaviors, changes in caregiving



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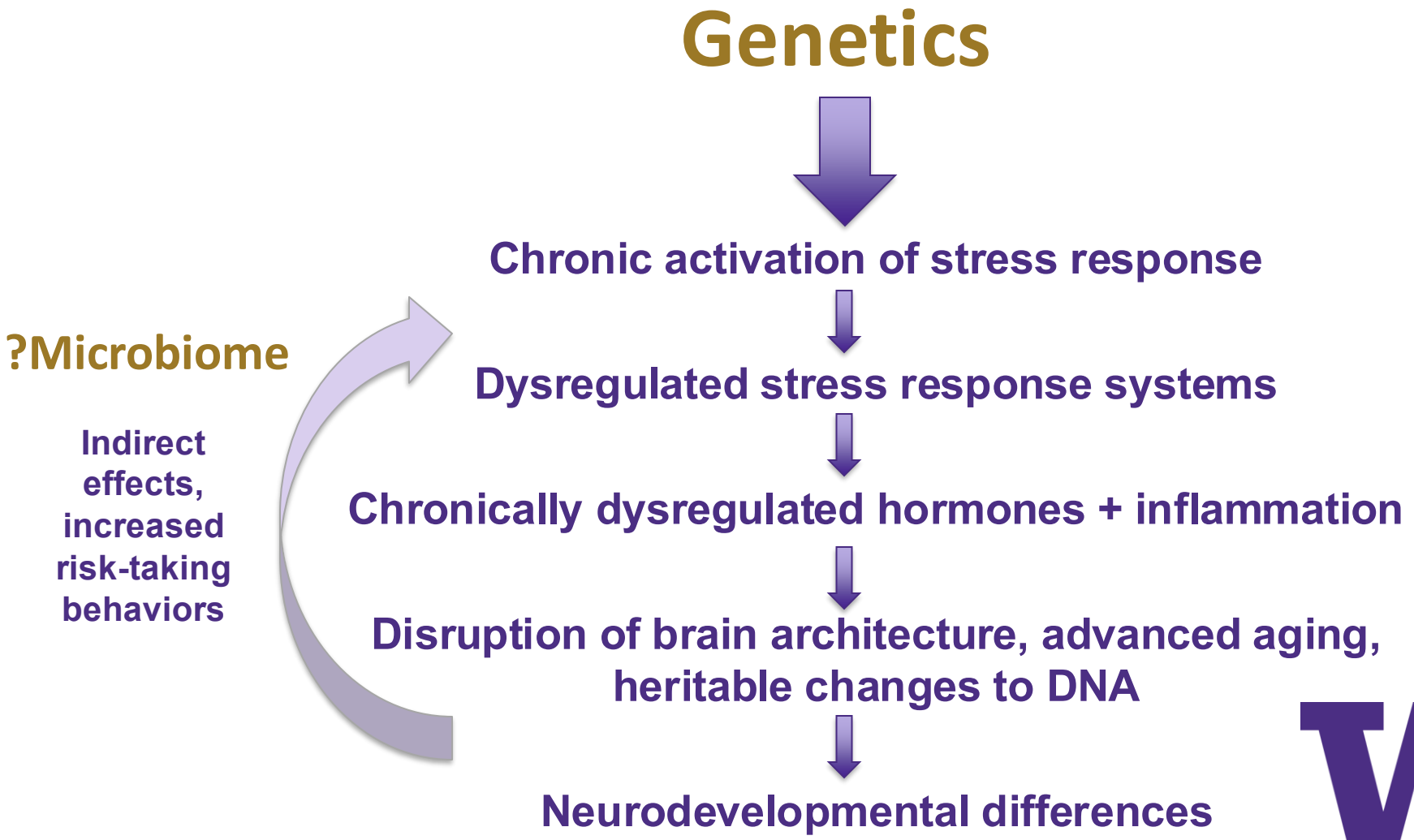

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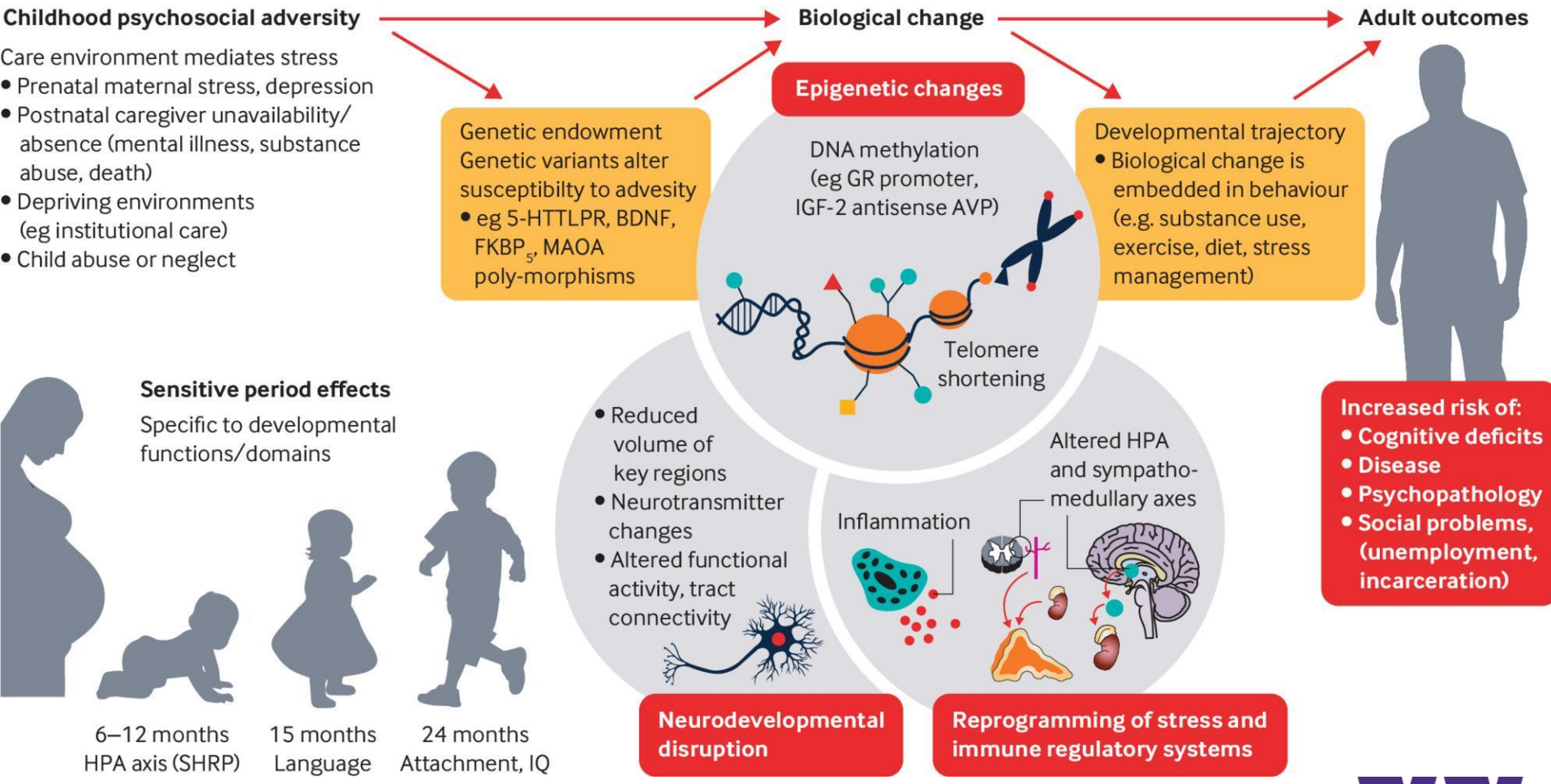

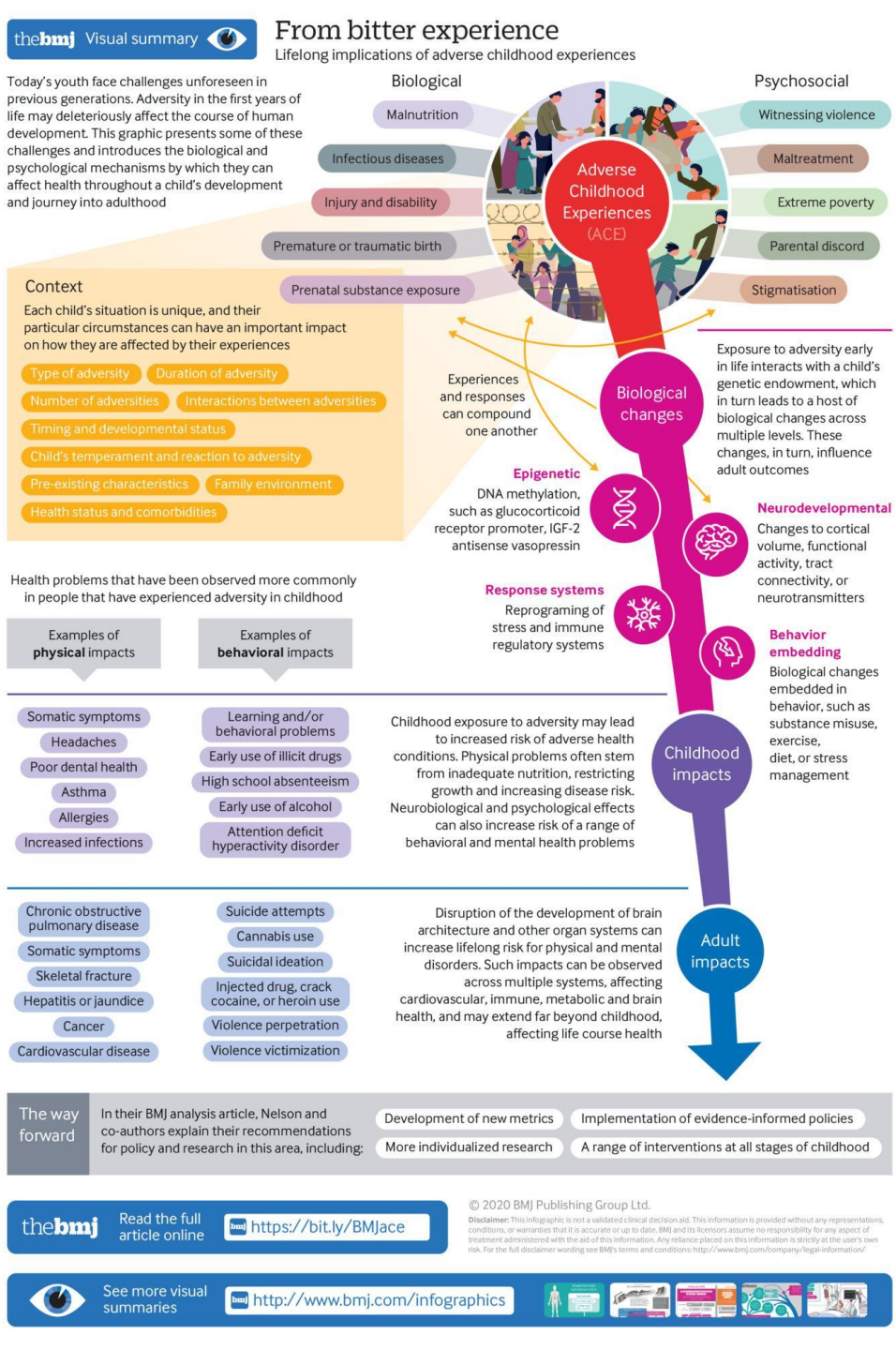

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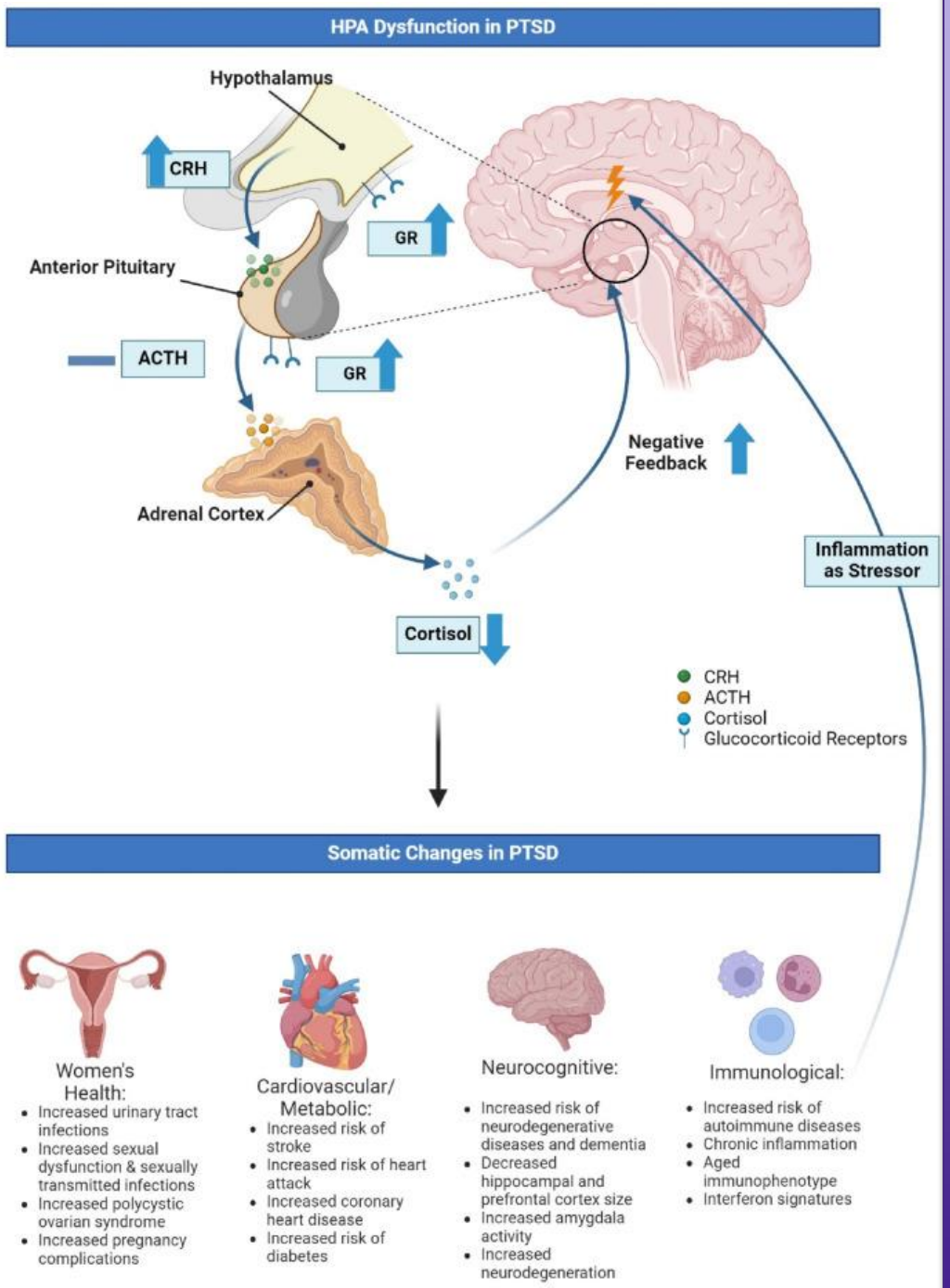
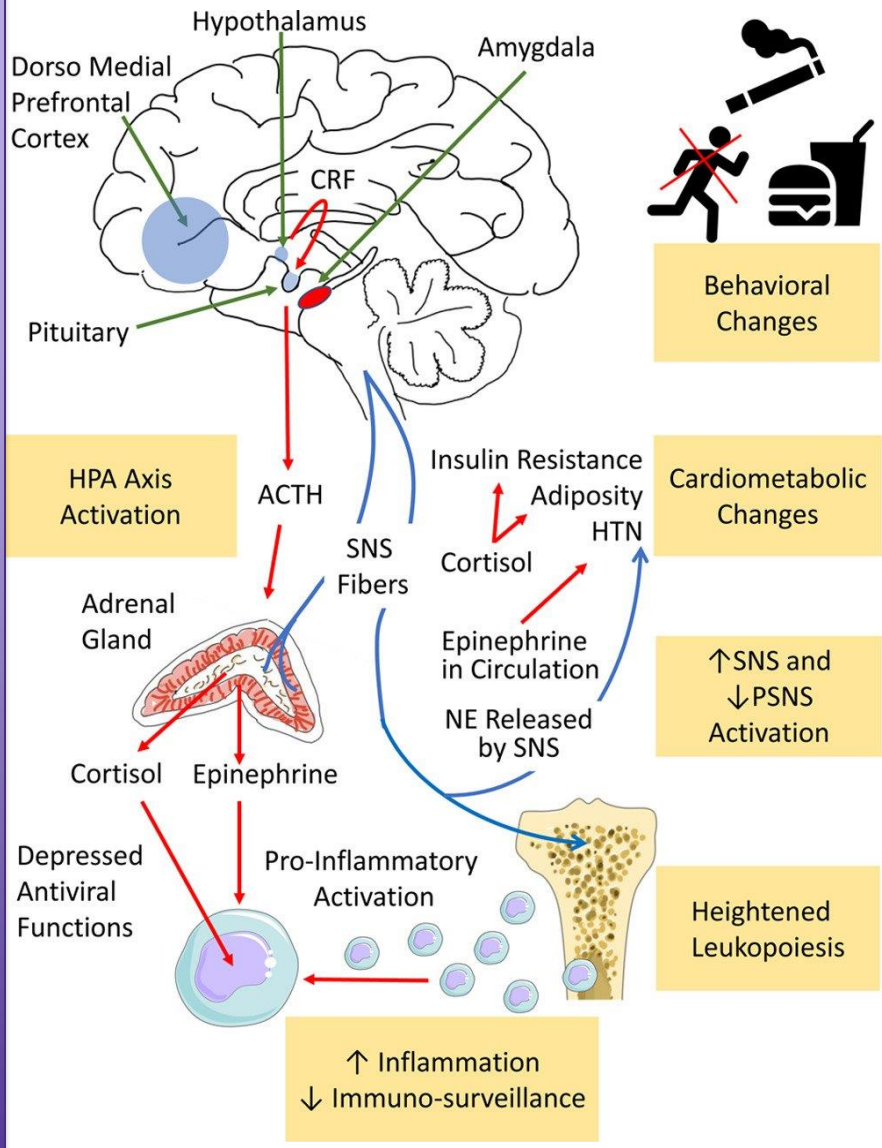

HPA Dysfunction in PTSD
Hypothalamus
CRH
GR
Anterior Pituitary
ACTH
GR
Negative Feedback
Adrenal Cortex
Inflammation as Stressor
Cortisol
CRH
ACTH
Cortisol
Glucocorticoid Receptors
Somatic Changes in PTSD
Women's Health:
Increased urinary tract infections
Increased sexual dysfunction & sexually transmitted infections
Increased polycystic ovarian syndrome
Increased pregnancy complications
Cardiovascular/ Metabolic:
Increased risk of stroke
Increased risk of heart attack
Increased coronary heart disease
Increased risk of diabetes
Neurocognitive:
Increased risk of neurodegenerative diseases and dementia
Decreased hippocampal and prefrontal cortex size
Increased amygdala activity
Increased neurodegeneration
Immunological:
Increased risk of autoimmune diseases
Chronic inflammation
Aged immunophenotype
Interferon signatures


Hypothalamus
Dorso Medial Prefrontal Cortex
Amygdala
CRF
Pituitary
Behavioral Changes
HPA Axis Activation
ACTH
Insulin Resistance
Adiposity
HTN
Cardiometabolic Changes
SNS Fibers
Cortisol
Adrenal Gland
Epinephrine in Circulation
↑SNS and ↓PSNS Activation
NE Released by SNS
Cortisol
Epinephrine
Depressed Antiviral Functions
Pro-Inflammatory Activation
Heightened Leukopoiesis
↑ Inflammation
↓ Immuno-surveillance

Trauma and IDD

Trauma can contribute to the cause of I/DD.

People with I/DD are much more likely to experience trauma.

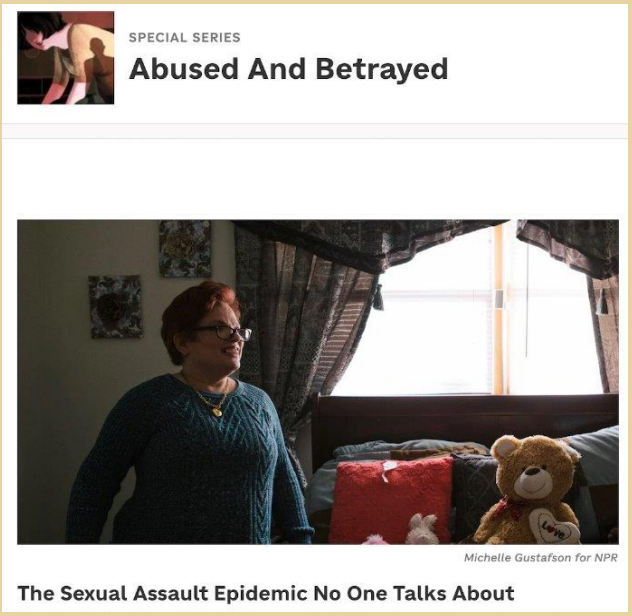
- 2-7x more likely to experience maltreatment of all types than neurotypical peers
  - 31% vs 9% in one study
- 4x rate of violent victimization
  - 1 of 3 robbery victims
  - 17.2% victim or witnessed violent incident in their neighborhood (compared to 5.3%)
- Maltreated children up to 7x more likely to be diagnosed with IDD
- More ACEs → later diagnosis
- **Stats on this topic are underestimates.**

The Silent Epidemic: Sexual Violence

- At least 7x rate of rape/sexual assault of people with ID
- One study found ~40% of disabled women have been sexually assaulted
- 39% female victims of rape identify as disabled
- Children with I/DD 3-5x more likely to experience sexual abuse
- Perpetrator usually well known to victim (<14% rapists against those with I/DD were strangers vs 24%)
- 19% of sexual assaults against people with I/DD are reported compared to 36% against non-disabled people
- Frequently occurs more than once

Contributing Factors

- We aren't asking or identifying signs.
  - Speaking to caregivers only
- Assumptions regarding sex and sexuality
- Lack of age-appropriate sex education at developmentally-appropriate level
  - Denied language to describe what happened to them
- Caregivers as perpetrators
  - Conditioned to comply with authority
  - Difficulty distinguishing between safe and unsafe touch



Common Scenarios: Other Abuse and Neglect

- Children with I/DD nearly 4x more likely to be physically abused (inversely related to severity of disability)
- More common in non-speaking patients
- Typically more severe and repeated over longer period
- Financial exploitation and intimate partner violence against adults with I/DD
- Medical neglect

Common Scenarios: At Home

- Financial, emotional, physical family stressors
  - Complicated health and education systems
  - Lack of resources, therapies, respite
  - Accessibility challenges
  - Symptoms: emotional dysregulation, sleep difficulties
- Increased rates of:
  - Abuse and neglect
  - Divorce
  - Mental illness, substance use disorders
  - Caregivers in legal system
  - Death of caregivers
- Risk of financial exploitation
- Residential centers/institutionalization
  - Sudden changes, multiple placements

Common Scenarios: Foster Care

- 2x more likely to be in foster care than children without disabilities
- Children with special health care needs comprise 24% of children in foster care (83% in IL, 26% in WA)
- Need for specialized trainings
- Delays in care: administrative delays, gaps in care, inconsistent medical records
- Once placed in foster care:
  - More likely to experience longer foster placements, placement instability and adoption disruption
  - Less likely to be reunified with family member

Common Scenarios: Schools

- Restraint, restriction and seclusion/use of adverse behavioral management techniques
  - Self-contained classrooms
  - State laws often unclear, contradictory or varied regarding these techniques
  - Medical setting too
- Inadequate resources, time for teachers
- Bullying
- Cyber safety

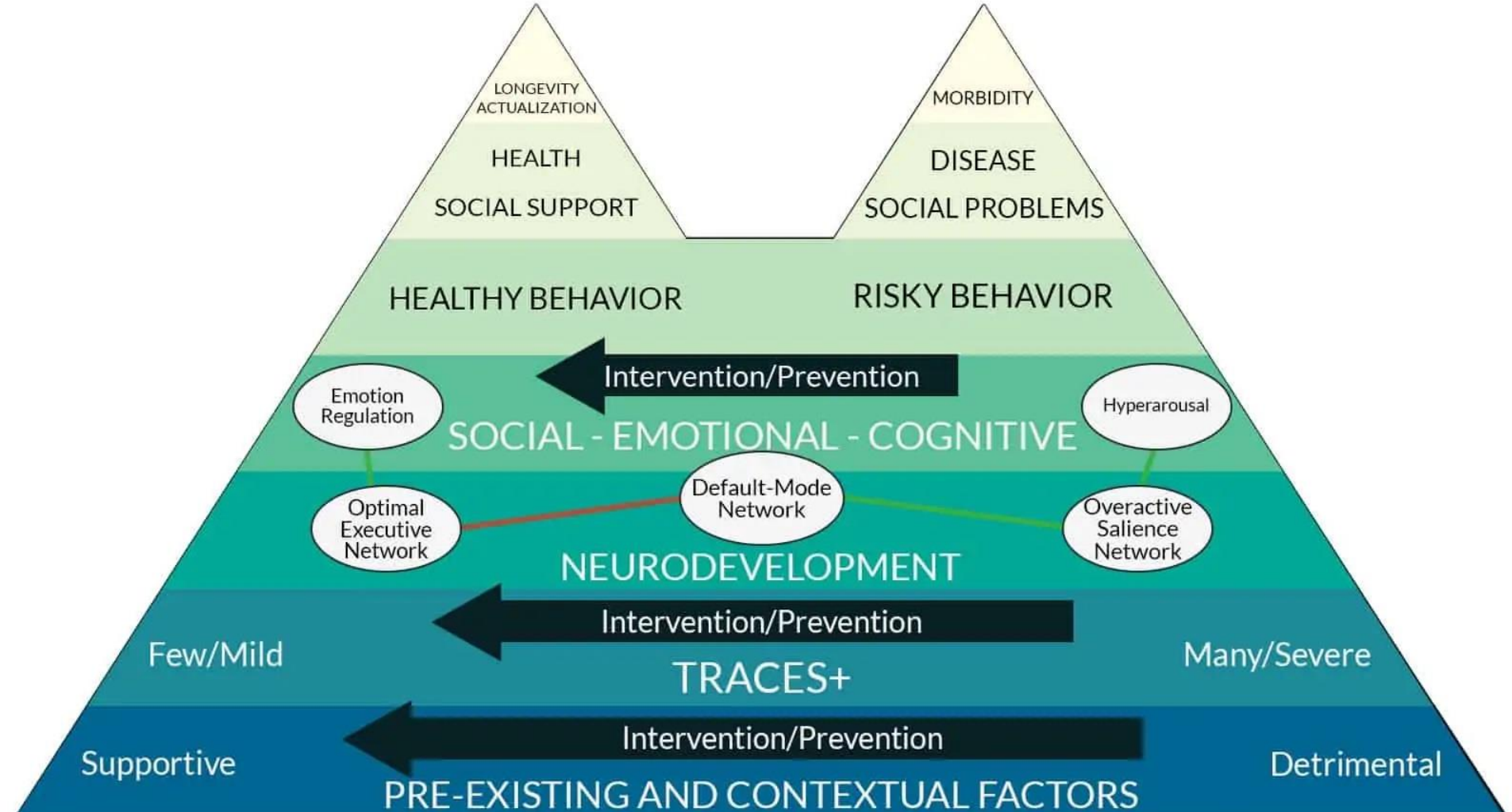
Common Scenarios: Policing, Criminal Legal System, Civil Commitment

- Police interaction
  - Alternatives to police presence underutilized or unavailable
  - Safety resources
- Incarceration
  - Isolation and restraint
- Civil Commitment and Involuntary Treatment Act

Barriers

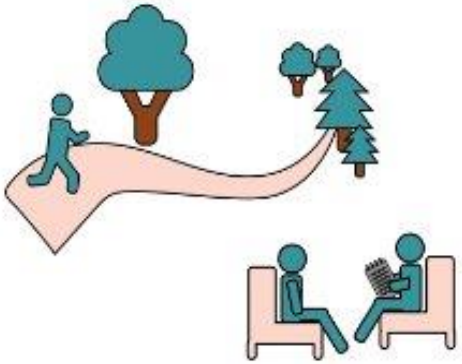
- Lack of adequate screening tools
- Diagnostic overshadowing
- Communication differences
- Institutionalization/group homes
- Not believed
- Lack of accessibility in criminal legal system
  - Includes reporting, accessing lawyers, trial
  - Very difficult to get representation
- Lack of providers with expertise in this area
- Lack of well-designed research studies with good standards of measurement
- Policymakers often not aware/interested

Resiliency


LONGEVITY ACTUALIZATION
MORBIDITY
HEALTH
DISEASE
SOCIAL SUPPORT
SOCIAL PROBLEMS
HEALTHY BEHAVIOR
RISKY BEHAVIOR
Intervention/Prevention
Emotion Regulation
Hyperarousal
SOCIAL - EMOTIONAL - COGNITIVE
Default-Mode Network
Optimal Executive Network
Overactive Salience Network
NEURODEVELOPMENT
Intervention/Prevention
Few/Mild
Many/Severe
TRACES+
Intervention/Prevention
Supportive
Detrimental
PRE-EXISTING AND CONTEXTUAL FACTORS

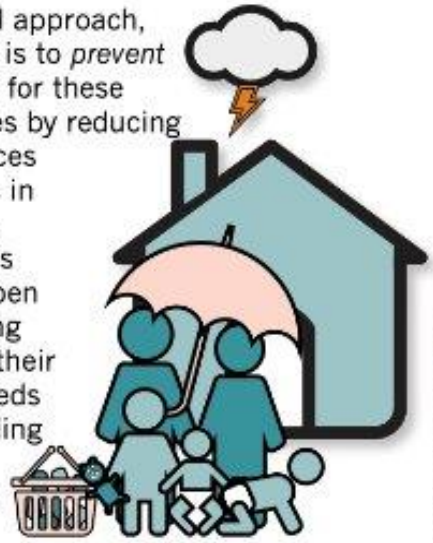
Resiliency

WE CAN REDUCE THE EFFECTS OF ACES AND TOXIC STRESS.



For those who have experienced ACEs, there are a range of possible responses that can help, including therapeutic sessions with mental health professionals, meditation, physical exercise, spending time in nature, and many others.

The ideal approach, however, is to *prevent* the need for these responses by reducing the sources of stress in people's lives. This can happen by helping to meet their basic needs or providing other services.



Likewise, fostering strong, responsive relationships between children and their caregivers, and helping children and adults build core life skills, can help to buffer a child from the effects of toxic stress.

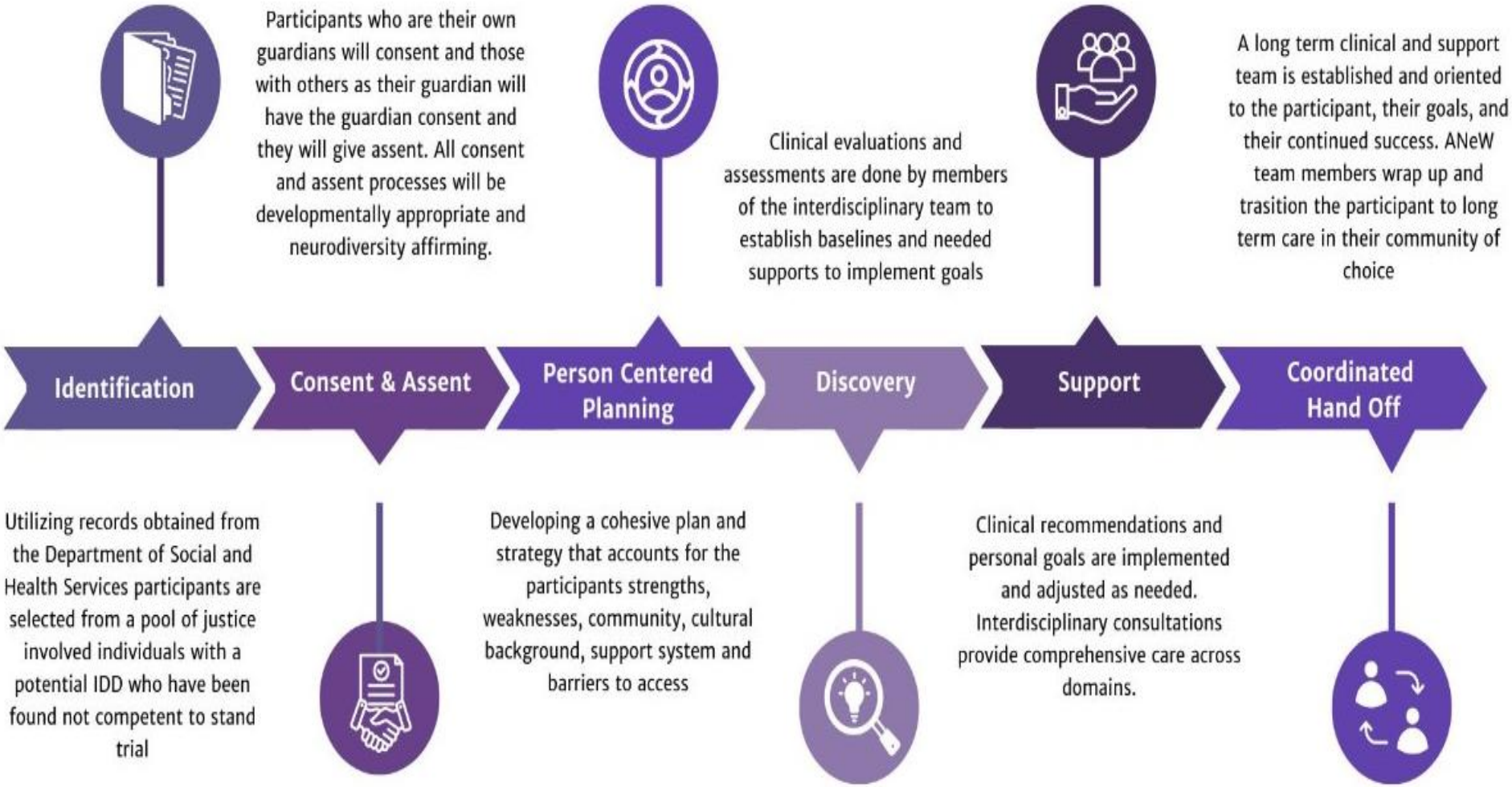
Neurodevelopmental Disability in the Criminal Legal System

- Individuals with Intellectual and Developmental Disabilities have a high co-occurrence of Mental Illness
- Cognitive disability contributes to an increased incidence in first responder calls, emergency room visits, hospitalizations, and arrests
- Medical, educational, and social service supports reduce these events but can be difficult to access especially in underserved communities
- Successful diversion and recidivism reduction is difficult due to the lack of appropriate, coordinated, and accessible services

The Trueblood Class Action Suit, SSB5440, and IDD

- In 2015, a class action lawsuit known as the Trueblood Case determined that Washington state had failed to provide some adults with neurodevelopmental disabilities (as well as other physical and mental health conditions) with legally entitled services.
- Senate Bill 5440 passed in 2023 included the establishment of a crisis stabilization and support team at the University of Washington to provide recommendations and develop a pilot program intended to restore arrested adults with IDD to their communities.

UW Interdisciplinary Pilot Program



Program Aims

Describe population demographics, background, as well as identify facilitators and barriers to community reintegration

- *Provide interdisciplinary transitional services to support participants in safe & successful community re-integration*
- Identify and analyze protective and risk factors for the IDD Trueblood population

Key Preliminary Findings

Retrospective Chart Review & Interdisciplinary Pilot

- **Population is primarily male, low educational attainment, lacking family, community and service supports**
- **High rates of housing instability**
- **Significant instances of foster care and early childhood trauma**

Conclusion

- The interactions between trauma and I/DD is complicated and can be cyclical.
- People with I/DD face many barriers that increase their risk of trauma as well as prevent reporting and justice.
- The ANeW team is working to mitigate some of these barriers through multidisciplinary research and care.

References and resources available upon request.

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