

Managing Your Mental Health with Autoimmune Polyglandular Syndrome Type-1 (APS-1)

Maryland Pao, M.D.

Clinical & Deputy Scientific Director, NIMH, NIH

paom@mail.nih.gov

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National Institute
of Mental Health

Disclosure



The views expressed in this presentation do not necessarily represent the views of the NIH, DHHS, or any other government agency or official. I have no financial conflicts to disclose. I am a developer of the ASQ , Voicing My CHOICES and Checking In.

Learning Objectives

Participants will be able to:

Name 2 theories of normal childhood development

Recognize factors that affect coping with medical illness

Name 3 factors that help build resilience to challenges

Our Task in Pediatric Care

“To maximize children’s functional abilities and sense of well-being, their health-related quality of life, and their development into healthy and productive adults.”

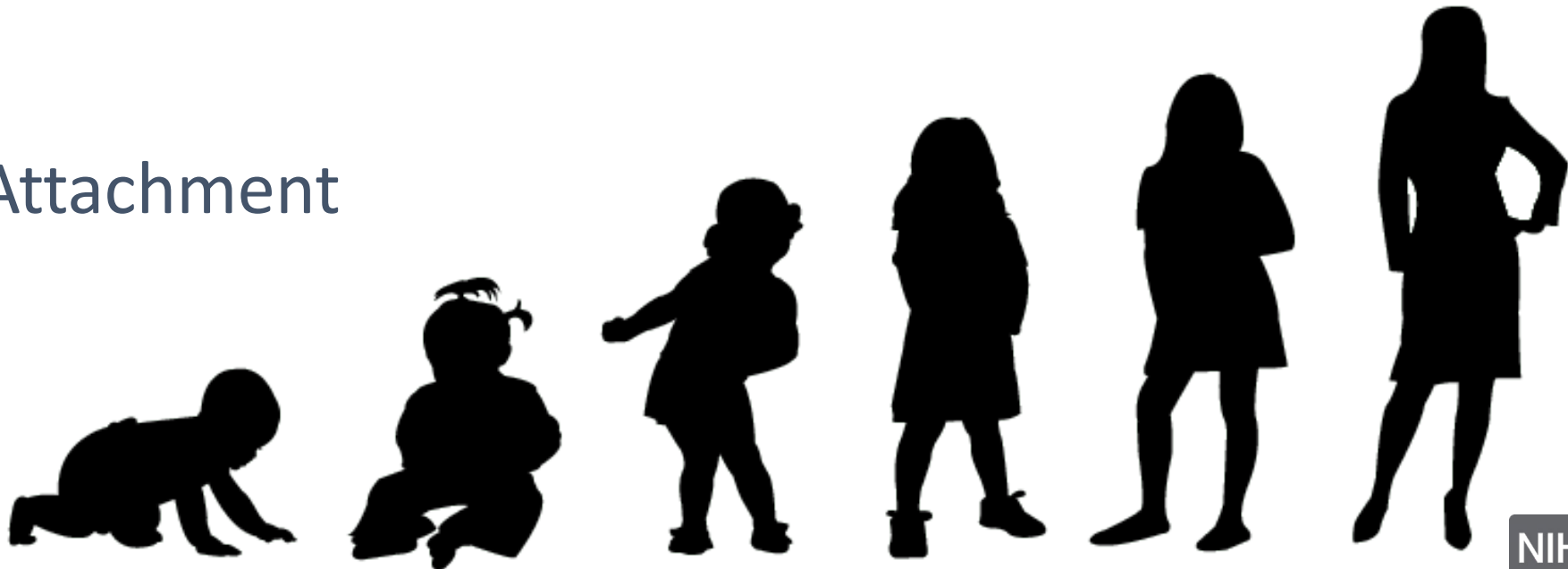
(AAP Policy on Psychosocial Risks of Chronic Health Conditions in Childhood and Adolescence, 1993)

- Why do some children with medical illnesses thrive and others not?
- What are the modifiable factors?

Developmental Trajectories

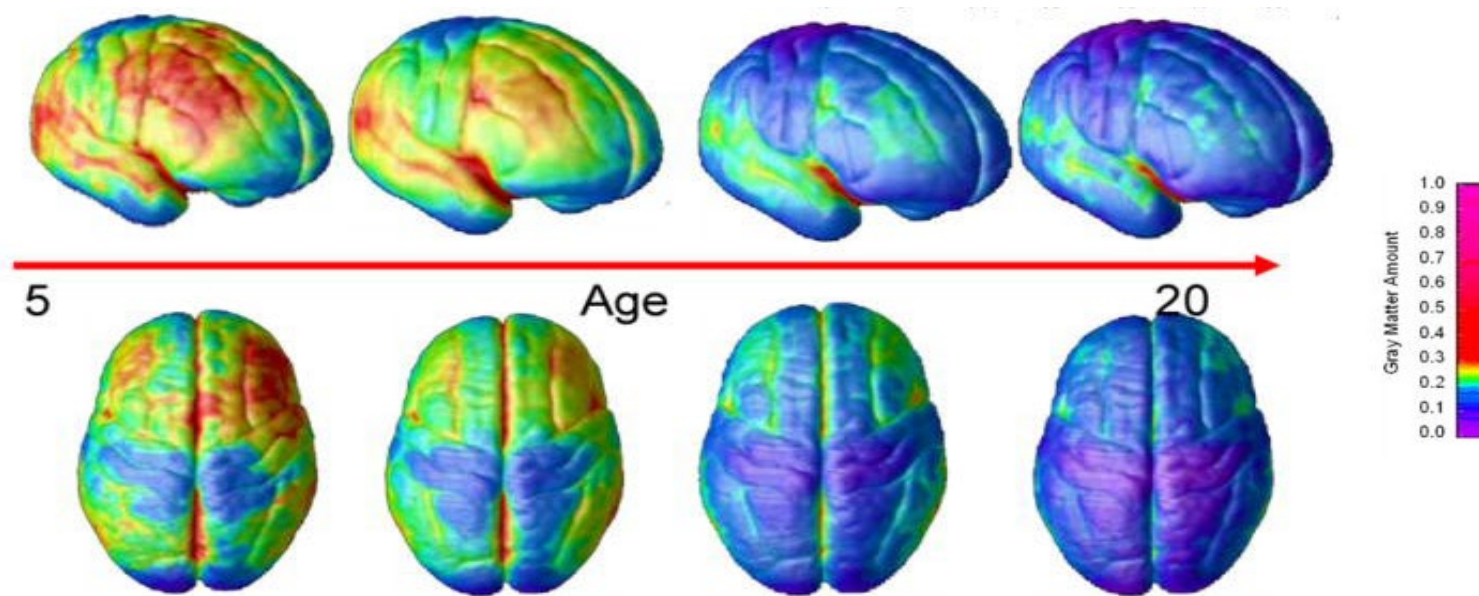
- ✓ Physical growth
- ✓ Motor development
- ✓ Language
- ✓ Cognitive

- ✓ Emotional/Attachment
- ✓ Sexual



The Developing Brain Across the Lifespan

- Different regions of the brain mature at different times in different places, at different rates in girls and boys
- The frontal cortex of the brain does not fully mature until around 25 years



Piaget: Theory of Cognitive Development

Systematic and predictable order

- Sensorimotor (0-2yr)
- Preoperational (2-7yr)
- Concrete operational (7-11yr)
- Formal operational (11yr to adult)

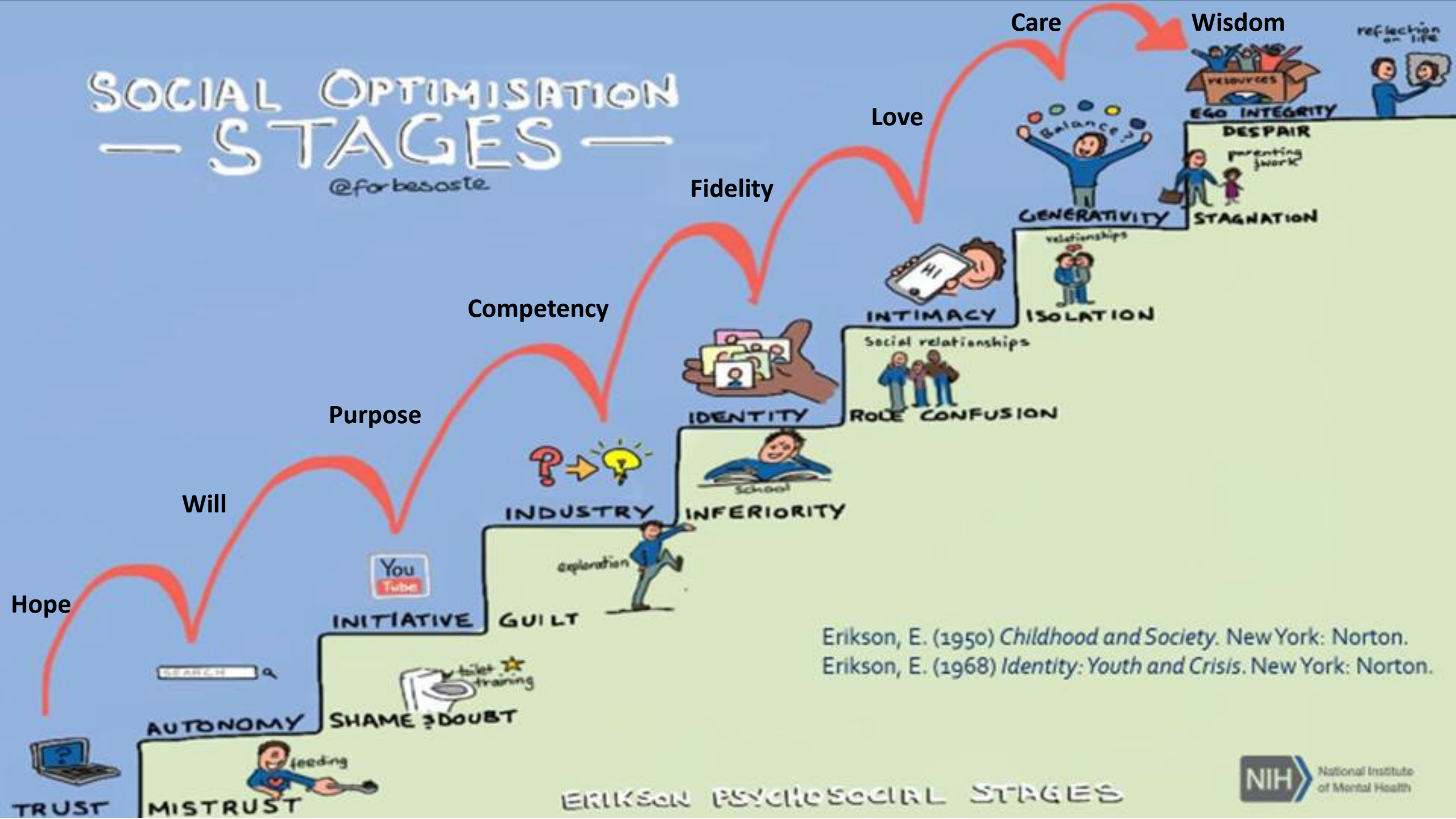


(Actual age in years may not be the same as the developmental age)

Piaget, J. (1990). The child's conception of the world. New York: Littlefield Adams.

SOCIAL OPTIMISATION — STAGES —

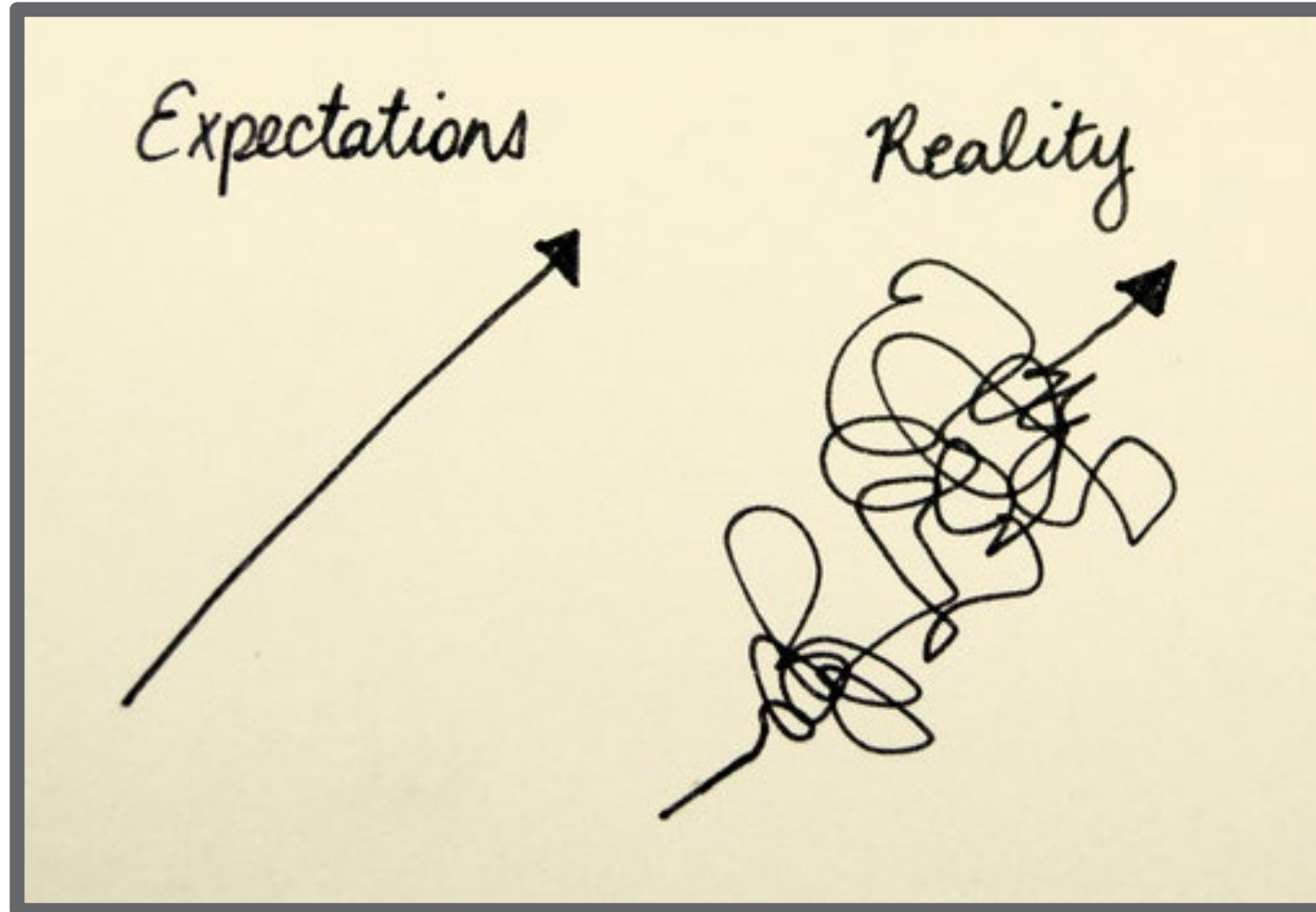
@forbesoste



Erikson, E. (1950) *Childhood and Society*. New York: Norton.
 Erikson, E. (1968) *Identity: Youth and Crisis*. New York: Norton.

ERIKSON PSYCHOSOCIAL STAGES

One Problem



Chronically Ill Children in Adulthood

- Elevated use of healthcare services, more hospital days
- Poorer school attendance
- Lower academic achievement
- Less permanent employment
- More likely to have delayed independence
- More likely to be single



Can this be prevented?

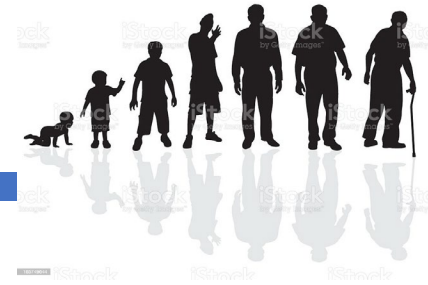
YES! BUT IT TAKES WORK!

- **HAVE EXPECTATIONS!**
- Elevated use of healthcare services-opportunities to evaluate whole person including mental health
- Poorer school attendance-what's important about school? social connection, routine, learning to live with others (emotional regulation, distress tolerance, rules-work ethic, right and wrong, boundaries, respect, empathy, communication skills), knowledge
- Lower academic achievement-remember 'practical life' skills
- Less permanent employment-school skills and independence; vocational or other skills, have expectations; other systems change needed?
- More likely to have delayed independence-parents need to deal with guilt, help kids stay on trajectories as much as they can
- More likely to be single-we need to foster competence and confidence

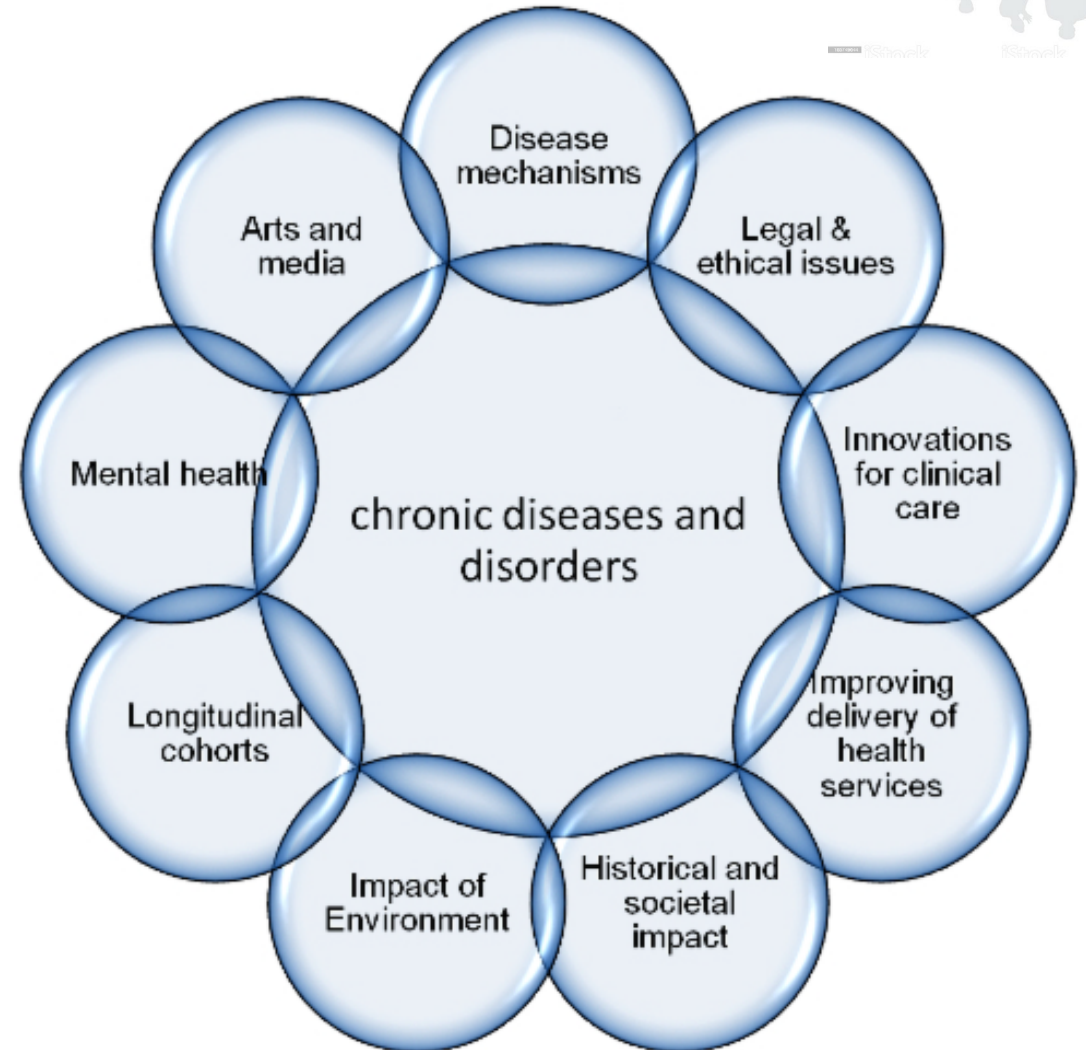
Factors That Affect Adaptation to Chronic Illness

- Age at onset of illness
- Person's intelligence, temperament, and **social competence**
- Person's previous experiences with illnesses
- Nature and severity of the illness, associated suffering, potential for recurrence
- **Required treatments, adherence**
- **Coping skills**
- **Family and community factors**

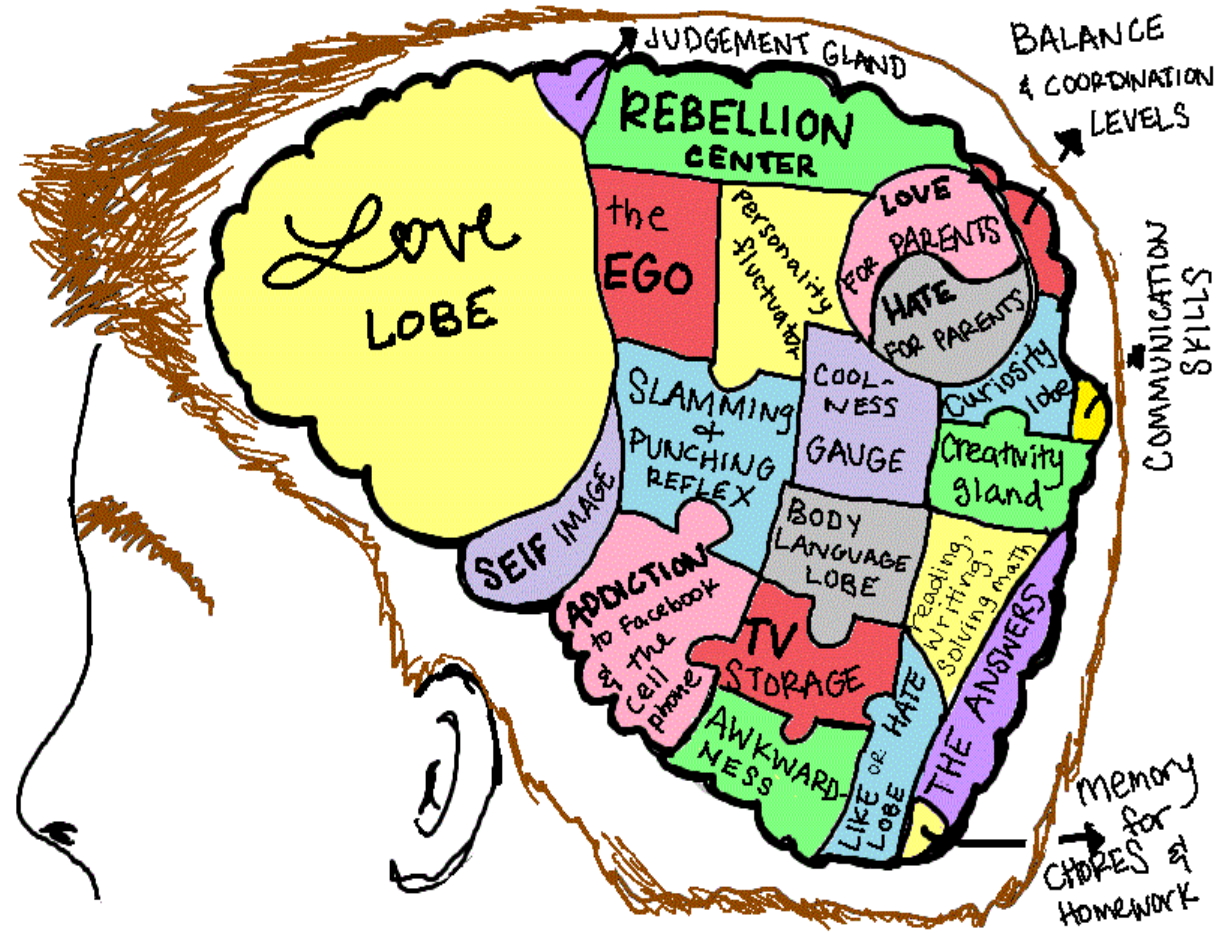
Developmental Trajectories



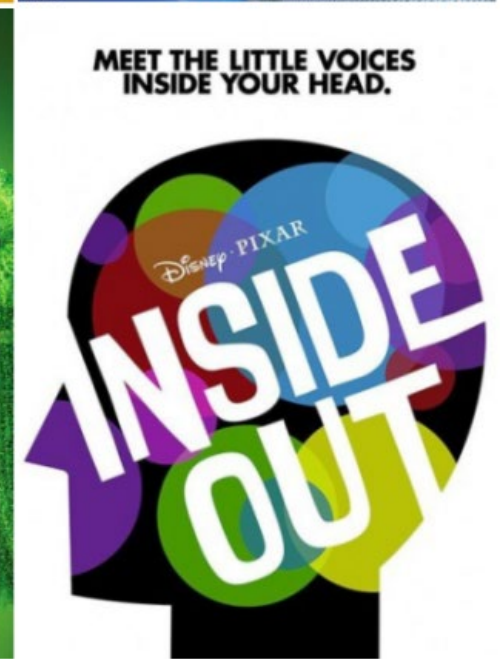
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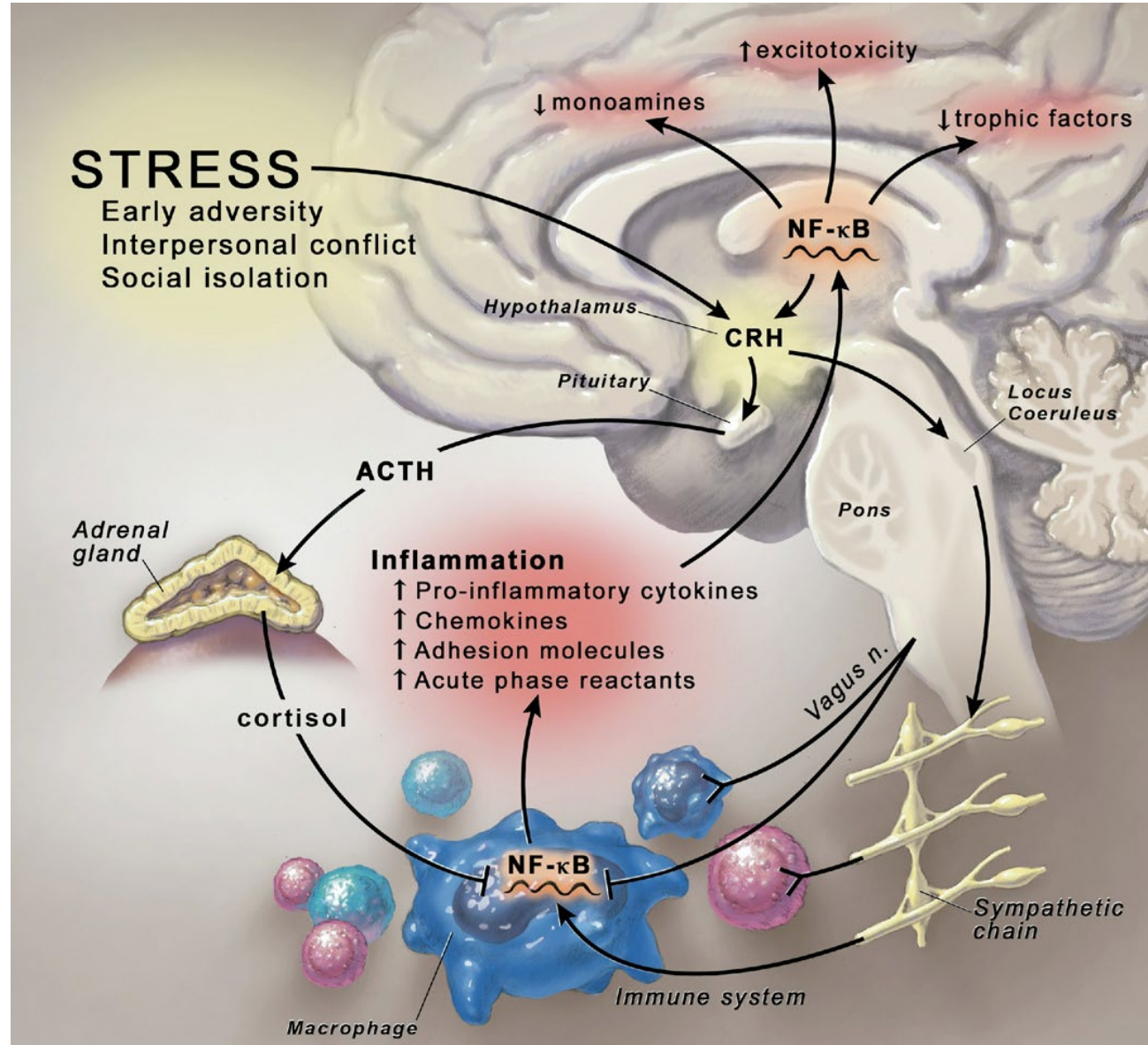
THE AVERAGE TEENAGE BRAIN



Got Emotions?



Stress-Induced Inflammatory Response



Period of new onset of major psychiatric disorders

- **50%** of all lifetime cases of mental illness begin by age 14
- **75%** begins by age 24

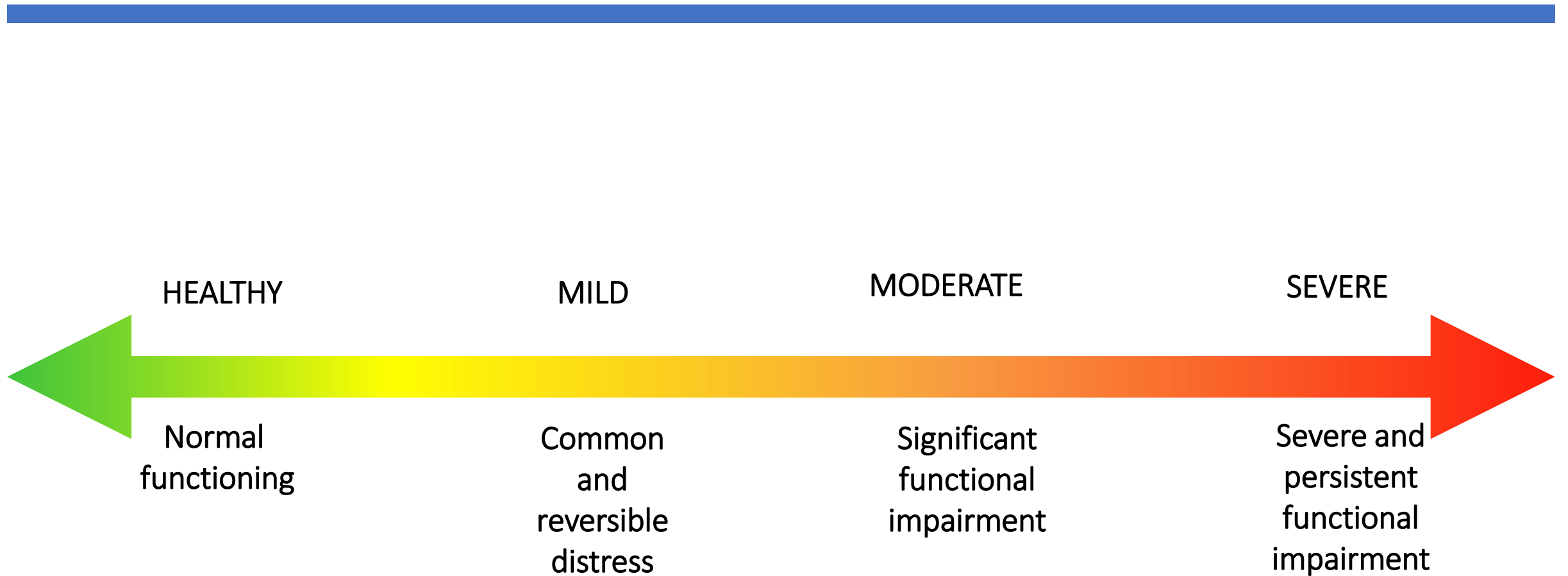
Spectrum of Clinical Concerns

Normal ↔ **Developmental Variation** ↔ **Problematic** ↔ **Disorder**

Behaviors

Frequency and Duration of Symptoms
Severity

Mental Health Continuum



Mental Health and Mental Illness

Mental Health

Capacity to think, feel, and act in ways that allow us to:

- Enjoy life
- Deal with challenges

Mental Health Issues

Diminished capacities that interfere with:

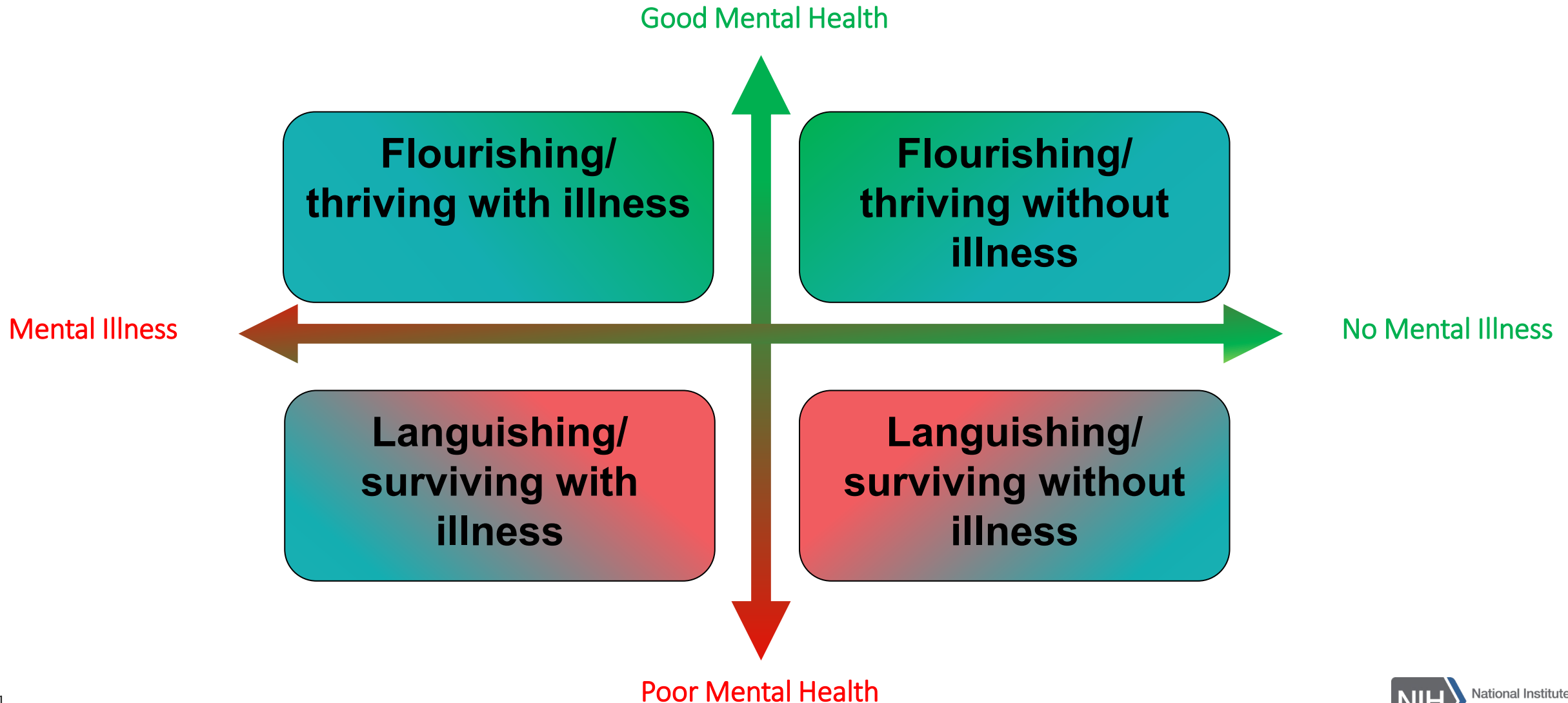
- Enjoyment of life
- Interactions with society and environment

Mental Illness

Conditions that affect a person's thinking, feelings, and behavior including:

- Depression
- Anxiety
- Post-traumatic stress disorder
- Schizophrenia

Corey Keyes' Dual Continuum Model



Challenges for clinicians when working with Adolescents and Young Adults (AYA)

When:

- Parents or professionals and AYA do not agree on their level of involvement or the decision itself
- AYA risk-taking (which is normal) impacts decisions about care
- Risky behaviors including sex, illegal substances, thoughts of self-harm or suicide are discussed and how best to document these while maintaining TRUST & Confidentiality

GOT TRANSITION?

-Transition from pediatric to adult health care is a process that is not marked by an age or a single event. Preparation is key.

-Consider developmental issues and don't underestimate the experience of loss by patients, families, and caregiver team

-Coordinated approach, communication between AYA and adult providers is ideal

-Create a health “passport”



- Empower with knowledge about themselves, treatment history and disease course
- Can be created with the pediatric provider and updated by the young adult
- Helps reduce the reassessment

GOT TRANSITION?



Side-by-Side Version Six Core Elements of Health Care Transition 2.0

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAPF/ACP Clinical Report on Transition.¹

Sample clinical tools and measurement resources are available for quality improvement purposes at www.GotTransition.org ■

Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)	Transitioning to an Adult Approach to Health Care Without Changing Providers (Family Medicine and Med-Peds Providers)	Integrating Young Adults into Adult Health Care (Internal Medicine, Family Medicine, and Med-Peds Providers)
1. Transition Policy <ul style="list-style-type: none"> Develop a transition policy/statement with input from youth and families that describes the practice's approach to transition, including privacy and consent information. Educate all staff about the practice's approach to transition, the policy/statement, the <i>Six Core Elements</i>, and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences. Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care. 	1. Transition Policy <ul style="list-style-type: none"> Develop a transition policy/statement with input from youth/young adults and families that describes the practice's approach to transitioning to an adult approach to care at 18, including privacy and consent information. Educate all staff about the practice's approach to transition, the policy/statement, the <i>Six Core Elements</i>, and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences. Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care. 	1. Young Adult Transition and Care Policy <ul style="list-style-type: none"> Develop a transition policy/statement with input from young adults that describes the practice's approach to accepting and partnering with new young adults, including privacy and consent information. Educate all staff about the practice's approach to transition, the policy/statement, the <i>Six Core Elements</i> and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences. Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.
2. Transition Tracking and Monitoring <ul style="list-style-type: none"> Establish criteria and process for identifying transitioning youth and enter their data into a registry. Utilize individual flow sheet or registry to track youth's transition progress with the <i>Six Core Elements</i>. Incorporate the <i>Six Core Elements</i> into clinical care process, using EHR if possible. 	2. Transition Tracking and Monitoring <ul style="list-style-type: none"> Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry. Utilize individual flow sheet or registry to track youth/young adults' transition progress with the <i>Six Core Elements</i>. Incorporate the <i>Six Core Elements</i> into clinical care process, using EHR if possible. 	2. Young Adult Tracking and Monitoring <ul style="list-style-type: none"> Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry. Utilize individual flow sheet or registry to track young adults' completion of the <i>Six Core Elements</i>. Incorporate the <i>Six Core Elements</i> into clinical care process, using EHR if possible.

Resilience is not the absence of struggle...It's messy.



It doesn't mean being immediately okay.

Contributors to Resilience

Self-awareness

Self-care

Internal locus
of control

Present-
centered
mindfulness

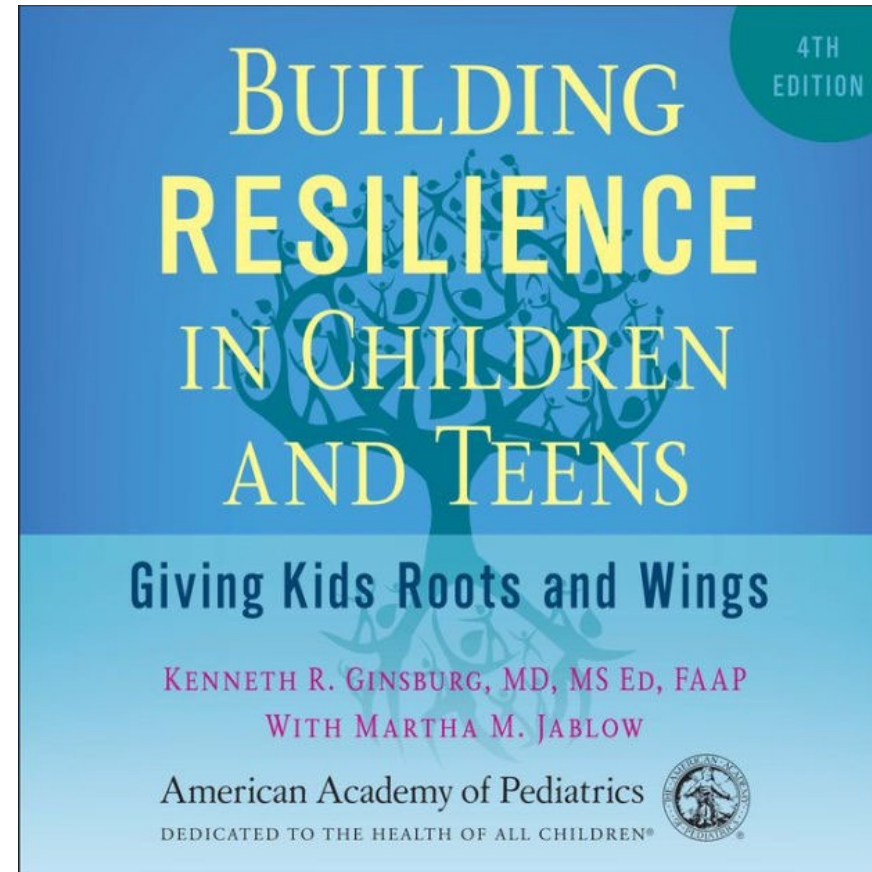
Connection

Growth and
gratitude
mindset

Sense of
meaning

Seven C's of Resilience

1. Control
2. Connection
3. Confidence
4. Character
5. Contribution
6. Coping
7. Competence

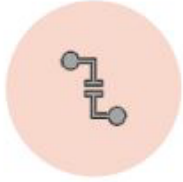


Ginsburg & Jablow, 2020

Stressors



GRIEF/GUILT



TENSION BETWEEN SPOUSES / SIBLINGS



ADJUSTING TO THE NEW "NORMAL" (NEW DX)



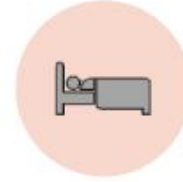
THERAPIST COMING IN/OUT OF THE HOME



TRYING TO ATTEND TO OTHER CHILDREN & THEIR ACTIVITIES



TANTRUMS; AGGRESSION/SELF INJURIOUS BEHAVIORS



SLEEP ISSUES



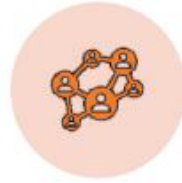
MEDICAL COMORBIDITIES/SPECIAL DIETS



CRITICISM FROM OTHERS; ADVICE FROM EVERYONE!



WORRY ABOUT WHAT THE FUTURE HOLDS



LOSS OF FRIENDS



FINANCIAL RESPONSIBILITIES



NAVIGATING SYSTEMS



UNCERTAINTY OF WHAT THE DAY HOLDS



ELOPEMENT



TAKING CHILD TO MULTIPLE THERAPIES

Antidotes to Distress?



Beauty
Awe
Humor
Love

APECED Patients at NIH (N=~130) & Mental Health

Chart review of 130 APECED patients seen at NIH over the past decade showed:

- 15 Psychiatry consults requested
- ~11.5% of total APECED followed at NIH
- 73% F (females tend to report more mental health symptoms and to seek more mental health help)
- 11-53 years old, mean age 24.8 years
- 15 patients that were not seen by the NIH Psychiatry Service also reported they were being treated for depression (12), bipolar disorder (2), unknown (1)

Most common questions for evaluation

Assistance in evaluating a symptom and/or diagnosing a mental health problem and how to manage it (in order of most frequent to least):

- Anxiety
- Mood lability
- Irritability
- Depression
- Suicidal thoughts (passive and active)
- Medication question-do I need one? Am I on the right one?
- Over focus on a physical symptom /conversion disorder
- ADHD
- Substance Use
- Hallucinations

APECED Patients at NIH (N= \sim 130) & Mental Health

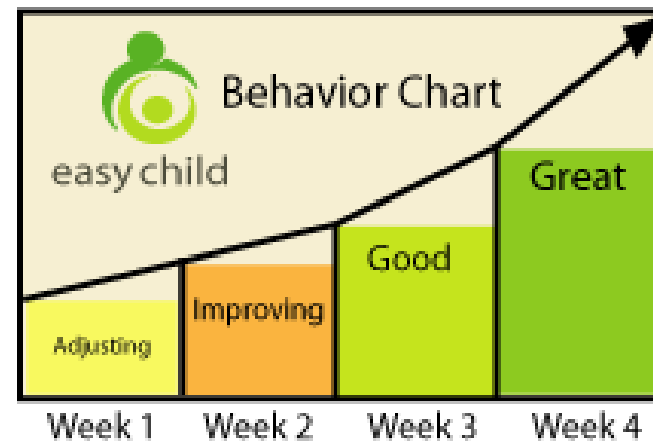
- In total, 30/130 (23%) reported a mental health diagnosis

➤ This is the same as in the general population.

- Medications patients were on: sertraline, fluoxetine, paroxetine, escitalopram, venlafaxine, mirtazapine, amitriptyline, aripiprazole, risperidone, oxcarbazepine, topiramate, lorazepam, clonazepam, alprazolam

➤ This is the same as in the general population.

Coping Around the World



When to possibly refer to Psychiatry

When child/adolescent/young adult has:

- Severe anxiety with panic
- Unremitting depressive symptoms with excessive guilt
- Suicidal thoughts or behaviors
- Confusion, hallucinations, agitation
- Homicidal thoughts or behaviors
- Aggression towards staff or family
- Current impairment in functioning due to symptoms
- Previous psychiatric history
- Strong family history of psychiatric disorders-especially immediate family member
- Current or history of psychiatric medication
- Concern for drug reaction or drug-drug interactions

OTHER QUESTIONS SPECIFIC TO HAVING APECED

- 1) How to reach out to other people with APECED experiencing the same issues?
- 2) How to cope with social anxiety because of having alopecia/enteropathy/other symptoms that can make people feel isolated?
- 3) Others?



Opportunity

- To prospectively gather information
- What psychosocial problems do you see most commonly in APS-1?
- Screening forms for anxiety, depression, suicidal ideation, attention problems, physical symptoms, other?



**OPPORTUNITY
AHEAD**

Possible future research



Checking IN

Evidence-informed digital
pediatric distress screener -
with optional EMR integration

Developed by researchers in the Pediatric Oncology Branch of the National Cancer Institute (NIH NCI), National Institute of Mental Health (NIMH) and technology through Patient Planning Services & Cancer Support Community

EXAMPLE: Standards for psychosocial care for children with cancer and their families

- Routine, systematic assessments of psychosocial health care needs
- Those at risk for neuropsychological deficits will receive regular monitoring
- Anticipatory guidance and annual screening for distress of survivors
- Access to psychosocial support and psychiatry as needed through the cancer trajectory
- Assessment and referral for financial hardship
- Availability of parental/caregiver mental health assessment and support
- Provision of psychoeducation (anticipatory guidance on the cancer trajectory)
- All youth should receive psychological intervention for medical procedures
- Provision of opportunities for social interaction during treatment and beyond
- Provision of supportive services for siblings
- Provision of coordination of school re-entry support
- Routine assessment of adherence throughout treatment
- Introduction to palliative care concepts
- Provision of bereavement follow up after a death
- Integration of trained pediatric psychosocial professionals with the medical team

EXAMPLE: Standards for psychosocial care for children with APS-1 and their families

- Routine, systematic assessments of psychosocial health care needs
- Those at risk for endocrine dysregulation will receive regular monitoring
- Anticipatory guidance and annual screening for distress across the lifespan
- Access to psychosocial support and psychiatry as needed through the APS-1 trajectory
- Assessment and referral for financial hardship
- Availability of parental/caregiver mental health assessment and support
- Provision of psychoeducation (anticipatory guidance on the APS-1 trajectory)
- All youth should receive psychological intervention for medical procedures
- Provision of opportunities for social interaction during treatment and beyond
- Provision of supportive services for siblings
- Provision of coordination of school re-entry support
- Routine assessment of adherence throughout treatment
- Integration of trained pediatric psychosocial professionals with the medical team

YOU HAVE A BLANK SLATE TO CREATE THE RESEARCH PSYCHOSOCIAL AGENDA FOR APS TYPE -1



Thank you!

Questions?



Resources

NIMH

[Health Topics, Mental Disorders, and Related Topics](#)

[Finding Help for Mental Illnesses](#)

National Organizations

[Mental Health First Aid](#)

[Anxiety and Depression Association of America](#)

[Depression and Bipolar Support Alliance](#)

[Mental Health America](#)

[National Alliance on Mental Illness](#)

More Mental Health Resources

AACAP - [Facts for Families Guide](#)

APA - [Best Practice Highlights: Working with Asian American Patients](#)

American Academy of Pediatrics

[Mental Health Initiatives](#)

[Blueprint for Youth Suicide Prevention](#)

[American Foundation for Suicide Prevention](#)

Mass General Hospital Center for Cross-Cultural Student Emotional Wellness
[COVID-19 and Racism \(available in Asian languages\)](#)

Stop APPI Hate – [List of resources and community-based organizations](#)

**Disaster
Distress
Helpline**

PHONE: 1-800-985-5990
TEXT: "TalkWithUs" to 66746
WEB: disasterdistress.samhsa.gov



**NATIONAL
SUICIDE PREVENTION
LIFELINE**
1-800-273-TALK (8255)
suicidepreventionlifeline.org

THE TREVOR PROJECT
LGBTQ CRISIS HOTLINE
CALL 1-866-488-7386

**988
SUICIDE
& CRISIS
LIFELINE**

**TRANS
LIFELINE**
1-877-565-8860

CRISIS TEXT LINE |
Text HELLO to 741741
Free, 24/7, Confidential

Spanish Resources

NIMH - [Información en español sobre la salud mental](#)

APA - [La Salud Mental](#)

SAMHSA - [Behavioral Health Spanish Language Resources](#)

French Resource

[Transcultural Mental Health Centre](#)

