Selected slides from : Life Course Theory and Social Determinants of Health (LCT-SDOH):

Application to work with and on behalf of children with special health care needs and their families

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Learning Objectives

Through participating in this session, LEND trainees will:

* **Describe key elements of LCT-SDOH**
* **Apply LCT-SDOH to work with and on behalf of children with developmental disabilities and their families**
* **Define "children with special health care needs" (CSHCN)**
* **Describe how child well-being is measured**
* **Consider how poverty affects child health and well-being**

Learning Objectives, cont.

* **Give examples of disparities in child health and well-being**
* **Discuss the impact of social stressors and difficult life circumstances on the children and families we serve and on our work with them**
* **Outline an approach to respond to families affected by stressors; suggest supportive strategies**

Key Elements
LCT/SDOH

Life Course Theory

* **Life Course is a theory or perspective that seeks to *understand, explain, and improve* health and disease patterns across population groups**
* **Theory is not new but science and its application expanding**

Life Course Core Concepts: "T2E2"

* **Today's experiences and exposures determine tomorrow's health (Timeline)**
* **Health trajectories are particularly affected during**

  critical or sensitive periods (Timing)

Fine, Kotelchuck, Addess, Pies 2009

Life Course Core Concepts: "T2E2"

* **The broader environment –biologic, physical, and social–strongly affects the capacity to be healthy (Environment)**
* **Inequality in health reflects more than genetics and**

  personal choice (Equity)

Fine, Kotelchuck, Addess, Pies 2009

Social Determinants of Health: an integral component of LCT

* **Elements of the "broader environment" – circumstances in which people are born, grow up, live, work, and age; systems of care- that can influence developmental and health outcomes.**
* **Includes: the family, education and income, interpersonal relationships, adequacy of housing, air quality and other environmental influences, and health care coverage.**
* **Shaped by a wider set of forces: economics, social policies, and politics**

Social Determinants of Health

* **Where we live, learn, work and play can have a greater impact on how long and well we live than medical care.**
* **A person's health and chances of becoming sick and dying early are greatly influenced by powerful social factors such as education, income, nutrition, housing and neighborhoods.**

Robert Wood Johnson Foundation Commission to Build a Healthier America; Issue Brief 7; December 2009

* **“This new perspective does not negate the importance of medical care but recognizes the need to look beyond it to the circumstances in which people live, work, learn and play.”**

Braverman and Barclay. Health Disparities Beginning in Childhood: A Life-Course Perspective. *Pediatrics* 2009; 124; S163-S175

Life Course Scholarship focuses on 2 key issues

* **Why do health disparities exist and persist across population groups?**

* **What are the factors that influence the capacity of individuals or populations to reach their full potential for health and well-being?**

Balance between individual responsibility and societal responsibility

"Unquestionably, individuals must take personal responsibility for their health and the health of their families, but individuals do not act in a vacuum. The contexts in which people live, learn, work, and play influence both the choices available to them and their ability to choose paths leading to health…..

Balance between individual responsibility and societal responsibility

"…. In many instances, the barriers to good health exceed an individual's abilities, even with the greatest motivation, to overcome these obstacles on his or her own. Children—who cannot choose their environments—are particularly vulnerable to the health damaging effects of harmful physical and social conditions, and childhood adversity often results in seriously diminished health in adulthood." Braverman, Egerter and Williams. The Social Determinants of Health: Coming of Age. *Ann Rev Public Health.2011. 32:381-398*

Evidence that the impact of adverse circumstances can be modified

* **"Substantial evidence indicates that pathways initiated by childhood adversity can be interrupted. Studies show that high-quality early childhood development interventions… greatly ameliorate the effects of social disadvantage in children's cognitive, emotional/behavioral, and physical development."** Braverman, Egerter and Williams. The Social Determinants of Health: Coming of Age. *Ann Rev Public Health.2011. 32:381-398*
* **Examples:**
  * **Parenting skills training**
  * **Family supports/networks**
  * **Supplemental nutrition**
  * **Home visiting**
  * **Early intervention**

Applying LCT-SDOH to work with and on behalf of children with developmental disabilities and their families

LCT/SDOH Discussion Board Assignment Responses 2013

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Social Determinants of Health and CSHCN

1. **Social Determinants affect health, development and well-being of <u>all</u> children (with or without SCHN)**
   - **Low maternal education, poor maternal mental health, lack of family networks, financial strain pose risks to early child development**
   - **Positive parenting can buffer effect of these negative influences on development**
2. **Impact of social determinants such as poverty and low parental education may be stronger/different in a family with a child with special needs**
3. **All children should have opportunities and support to reach their full capacity for health and well-being**

* **To apply the LCT/SDOH framework and science to our work with and on behalf of children and families, and to consider persistent disparities we need:**
  * **A standard definition of the populations**
  * **Measures/ outcomes/ indicators to compare**

Defining Terms
Describing Populations





Children with Special Health Care Needs (CSHCN)

* **A new definition in 1998**

* **A new, uniform definition was required to help with development and evaluation of systems to serve CSHCN**

Official Definition CSHCN

The Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as:

"those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

* Not mainly condition-specific
* Includes children “at risk for” as well as children who “have”

Definition of CSHCN

NSCSHCN ppt from federal gov.pdf - Adobe Reader

File Edit View Document Tools Window Help

11 / 59 74.9% Find

CSHCN Screener

Asks about 5 different health consequences:

1) Limited or prevented in ability to function
2) Prescription medication need/use
3) Specialized therapies (OT, PT, Speech)
4) Above routine use of medical care, mental health or other health services
5) Counseling or treatment for on-going emotional, behavioral or developmental problem

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a) Due to medical, behavioral or other health condition

AND

b) Condition has lasted or is expected to last for at least 12 months

To "screen in:"

- one of the five items must be true AND
- a) and b) must be true about that item

start | Desktop | Karen's documents | Microsoft Office Word 2003 | DCDB - Digital Curriculom... | My Network Places | iTunes | Webex ses... | 2- LEADD | Microsoft P... | CSHCN, Pre... | http://cshc... | NSCSHCN p...

9:17 PM Wednesday 1/23/2008

% of CSHCN who had parental report of (parents can report more than one):

* Allergies (**48.6%**)
* Asthma (**35.3%**)
* **ADD/ADHD (30.2%)**
* **Developmental Delay (17.6%)**
* Anxiety Problems (**17.1%**)
* **Behavioral or Conduct Problems (13.5%)**
* Depression (**10.3%**)
* Migraines or Frequent Headaches (**9.8%**)
* **Autism Spectrum Disorder (7.9%)**
* **Intellectual Disability or Mental Retardation (5.8%)**
* Epilepsy or Seizure (**3.1%**)
* Heart Problem (**3.0%**)
* Arthritis or Other Joint Problems (**2.9%**)
* **Down Syndrome (1.1%)**
* Muscular Dystrophy (**0.3%**)
* Blood Problems (**1.5%**)
* Cystic Fibrosis (**0.3%**)
* Diabetes (**1.7%**)
* Head Injury, Concussion or Traumatic Brain Injury (**1.4%**)
* **Cerebral Palsy (1.6%)**

(Survey of Children with Special Healthcare Needs 2009-2010)

2009-2010 Survey of CSHCN

* **By parent report (parents can choose as many categories as apply, so there is overlap)**
  * **5.8% ID/MR**
  * **13.5% Behavioral problem**
  * **7.9% ASD**
  * **17.6% Developmental delay**
  * **30% ADD/ADHD**

(Survey of Children with Special Healthcare Needs 2009-2010)

Measuring Child Health and Well-being

* What is it important to measure it?

Health and well-being of Children

* **What are some ways of describing/measuring child well-being?**
* **What indicators do we use to describe how well a certain group of children is doing?**

Your examples

Examples

* **Physical health (obesity rates, height, lead poisoning rates)**
* **Death rates (infant mortality, deaths in various age groups of childhood)**
* **School achievement (years of schooling, high school completion)**
* **Teenage pregnancy rate**

Examples of National MCH Title V Performance Measures/Outcomes Measures (reported by MCH divisions of all state and territorial health depts)

* **% of CSHCN age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.**
* **% YSHCN who received the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.**
* **Rate of birth (per 1,000) for teenagers aged 15 through 17 years.**

https://mchdata.hrsa.gov/TVISReports/MeasurementData/MeasurementDataMenu.aspx

Examples of National MCH Title V Performance Measures/Outcomes Measures (reported by MCH divisions of all state and territorial health depts)

* **Infant mortality rate per 1,000 live births (# deaths first year of life/1000 live births).**
* **Ratio of the black infant mortality rate to the white infant mortality rate**
* **Rate (per 100,000) of suicide deaths among youths aged 15 to 19**

https://mchdata.hrsa.gov/TVISReports/MeasurementData/MeasurementDataMenu.aspx

Having parameters that define a group (CSHCN) and measures and indicators of child well-being allows us to:

* **describe differences between groups**
* **track differences over time**
* **assess effectiveness of an intervention**

Disparities

* **Differences in outcomes/measures/indicators (including developmental outcomes and other health outcomes; educational outcomes) on which socially disadvantaged groups (eg people with low income or educational attainment or members of a group that historically has experienced discrimination*) systematically do worse.**

*** includes groups defined by race, ethnicity, disability, etc**

Disparities

* Know they exist; define them, define their magnitude
* (Get angry)
* What causes the disparities? What are the pathways by which adverse social determinants impact on outcomes/child well-being?
* Can we decrease the disparity?

* Start by looking at disparities in outcomes and status across income/SES and poverty level for all children, narrow it to CSHCN

United States	22%
Puerto Rico	56%
Mississippi	33%
Ohio	23%
New York	21%
New Hampshire	10%

Children in Poverty 2010

The share of children under age 18 who live in families with incomes below the federal poverty level. In 2010, a family of 2 adults and 2 children fell in the "poverty" category if annual income was below $22,113

Area	% of children under age 18 who live in families with incomes below the federal poverty level
United States	22%
Puerto Rico	56%*
Mississippi	33%
Ohio	23%
New York	21%
New Hampshire	10%

Data Source: Population Reference Bureau, analysis of data from the U.S. Census Bureau, Census 2000 Supplementary Survey, 2001 Supplementary Survey, 2002 through 2010 American Community Survey (http://datacenter.kidscount.org/data/acrossstates/Rankings.aspx?ind=43)

* **Note**: The District of Columbia, Puerto Rico and the U.S. Virgin Islands are not included in maps and rankings because comparisons on many indicators of child well being are not meaningful

* $22,113 per year
* $1843 per month

Disparities across SES/income levels

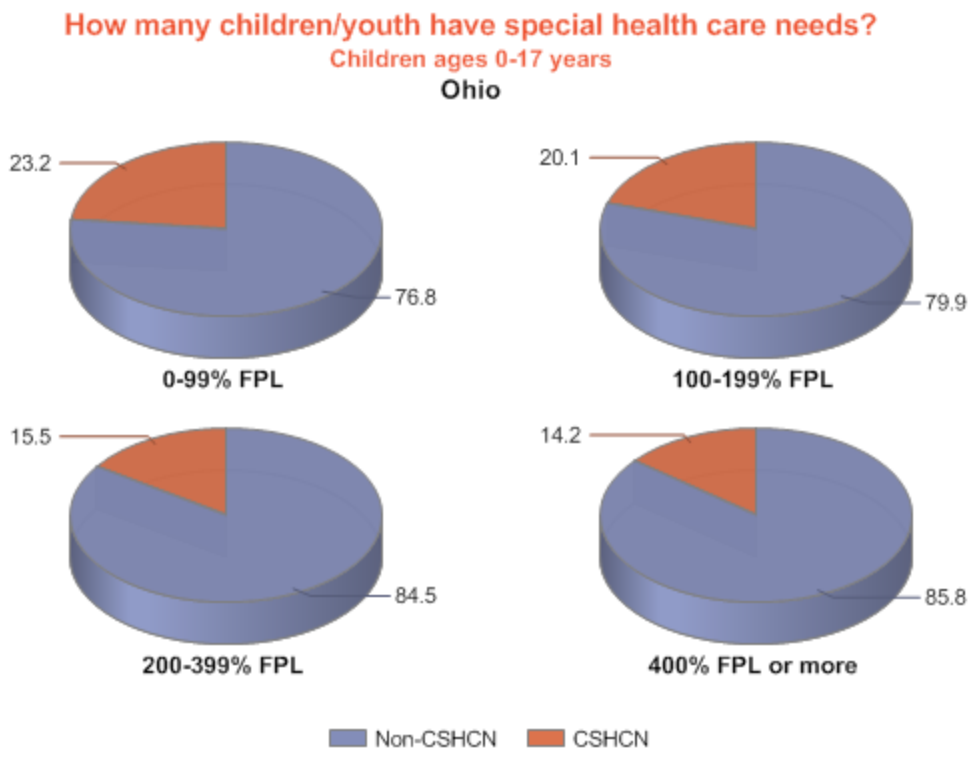
* **Children in poverty (compared to children not in poverty):**
  * **Are twice as likely (by parental report) to be in fair or poor health**
  * **Are 1.5 X as likely to die before the age of 14**
  * **Have 2X as many short-stay hospital episodes**
  * **As 16- to 24-year-olds, are 2.2 X more likely to either not be in school or not have finished school**
  * **Are 10X more likely to have experienced food insufficiency in the past year**
  * **Are 2X as likely to be afraid to go out in their neighborhoods**

Brooks-Gunn and Duncan; The effects of poverty on children; The Future of Children Fall 1997

Adult outcomes by poverty status between the prenatal year and age five

	Income below the official US poverty line	Income between one and two times the poverty line	Income more than twice the poverty line
	Mean or %	Mean or %	Mean or %
Completed schooling	11.8 yrs	12.7 yrs	14.0 yrs
Earnings ($10,000)	17.9	26.8	39.7
Annual work hours	1512	1839	1963
Poor Health	13%	13%	5%
Arrested (men only)	26%	21%	13%
Non-marital birth (women only(	50%	28%	9%

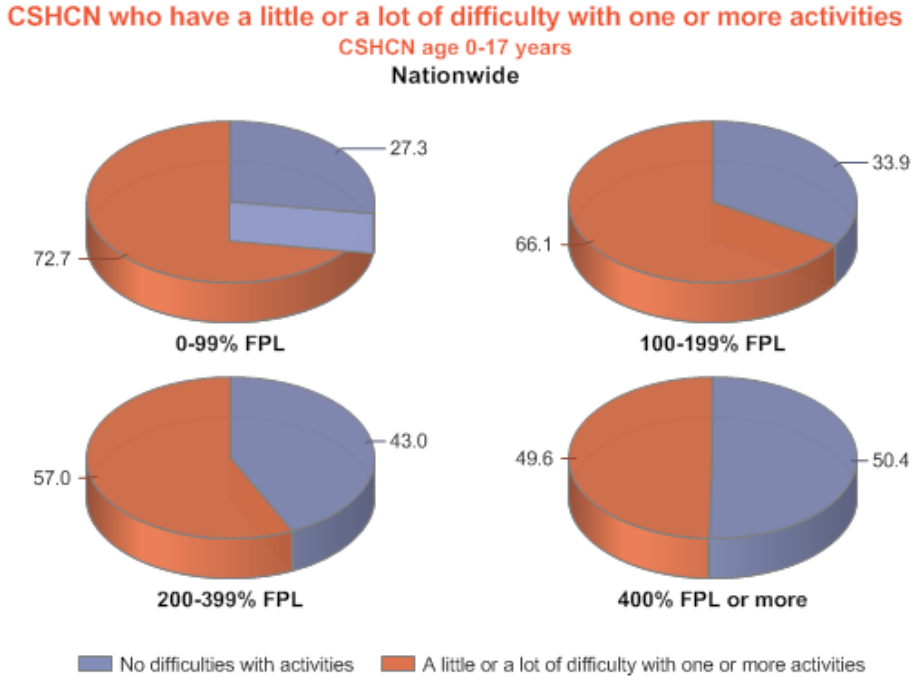
Disparities: differences in prevalence of SHCN by income level in Ohio



Survey: 2009/10 National Survey of Children with Special Health Care Needs
Starting Point: CSHCN Prevalence and Demographics
State/Region: Ohio

Disparities: % of CSHCN with difficulties across income levels

CSHCN who have a little or a lot of difficulty with 1 or more of the following: self care, coordination or moving around, using hands, learning, understanding or paying attention, speaking, communicating or being understood



Survey: 2009/10 National Survey of Children with Special Health Care Needs
Starting Point: MCHB Core Outcomes and Key Indicators
State/Region: Nationwid

Prevalence of DD across education and income gradients

* **Prevalence of any developmental disability in 1997–2008 was 13.87%**
* **Nearly twofold higher prevalence of any reported developmental disability among children insured by Medicaid relative to those insured by private insurance, and this pattern was statistically significant for ADHD, learning disabilities, intellectual disabilities, seizures, stuttering or stammering, and other developmental delays.**

Blumberg, Marshalyn Yeargin-Allsopp, Susanna Visser and Michael D. Kogan
Coleen A. Boyle, Sheree Boulet, Laura A. Schieve, Robin A. Cohen, Stephen J.; **Trends in the Prevalence of Developmental Disabilities in US Children, 1997**-2008. *Pediatrics* 2011;127:1034–1042

Prevalence of DD across education and income gradients

* **Family incomes below the federal poverty level associated with a higher prevalence of parent-reported developmental disabilities overall and learning disabilities, intellectual disabilities, stuttering or stammering, and other developmental delays, specifically.**
* **Lower maternal education (ie, any attainment less than a college degree) was associated with a higher prevalence of any developmental disabilities, learning disabilities, and stuttering or stammering.**

Blumberg, Marshalyn Yeargin-Allsopp, Susanna Visser and Michael D. Kogan
Coleen A. Boyle, Sheree Boulet, Laura A. Schieve, Robin A. Cohen, Stephen J.; **Trends in the Prevalence of Developmental Disabilities in US Children, 1997**-2008. *Pediatrics* 2011;127:1034–1042

Relationship of cognitive test scores to income levels

* **Children from low-income families have lower cognitive test scores when compared with children from more affluent backgrounds.**
* **The association remains even after statistical control for maternal cognitive skills, parent education, and family structure. It is estimated that children reared in poverty score between 15% and 40% of a SD lower on cognitive assessments than children from higher income backgrounds.**

Najman, Fassa et al. The Impact of Episodic and Chronic Poverty on Child Cognitive Development. The Journal of Pediatrics • February 2009

Relationship of cognitive test scores to income levels

* **Parent and grandparent socioeconomic status (SES) are independently associated with lower child cognitive development at 5 and 14 years of age**
* **Children experiencing family poverty at any developmental stage in their early life course have reduced levels of cognitive development, with the frequency that poverty is experienced predicting the extent of reduced cognitive scores**

Najman, Fassa et al. The Impact of Episodic and Chronic Poverty on Child Cognitive Development. The Journal of Pediatrics • February 2009

Possible pathways for poverty to impact children

* **Health and nutrition**
* **Home environment quality**
* **Care-giver interactions**
* **Parental mental health**
* **Neighborhood conditions/environment**
* **?common pathway: influence of stress on brain development?**

-----Original Message-----

From: NIH news releases and news items [mailto:NIHPRESS@LIST.NIH.GOV] On Behalf Of NIH OLIB (NIH/OD)

Sent: Tuesday, August 28, 2012 3:53 PM

To: NIHPRESS@LIST.NIH.GOV

Subject: STRESSES OF POVERTY MAY IMPAIR LEARNING ABILITY IN YOUNG CHILDREN

U.S. Department of Health and Human Services NATIONAL INSTITUTES OF HEALTH NIH News Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) <http://www.nichd.nih.gov/> For Immediate Release: Tuesday, August 28, 2012

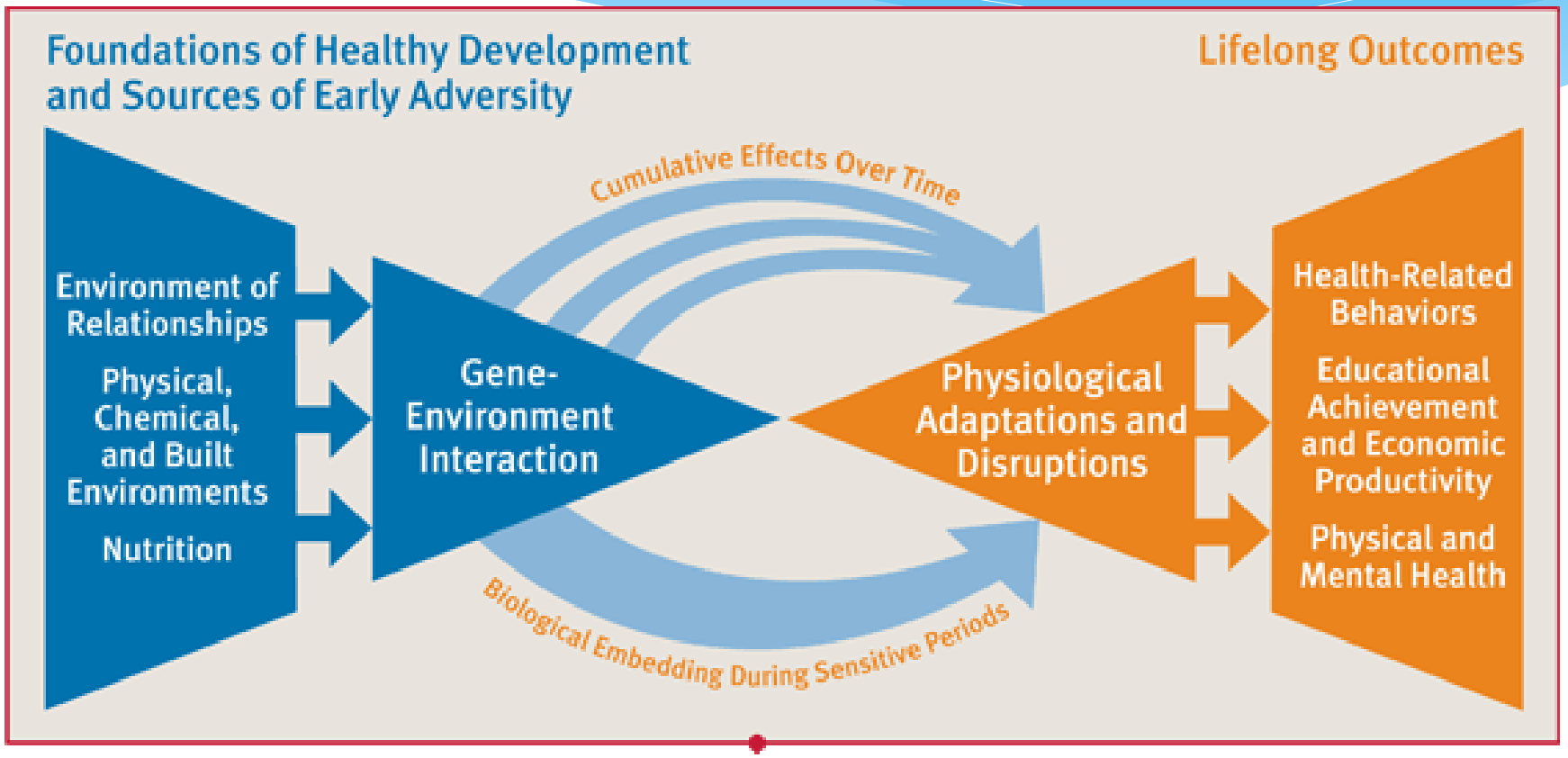
STRESSES OF POVERTY MAY IMPAIR LEARNING ABILITY IN YOUNG CHILDREN NIH funded research suggests stress hormones inhibit brain function, stifle achievement……..

* “The stresses of poverty -- such as crowded conditions, financial worry, and lack of adequate child care -- lead to impaired learning ability in children from impoverished backgrounds, according to a theory by a researcher funded by the National Institutes of Health. The theory is based on several years of studies matching stress hormone levels to behavioral and school readiness test results in young children from impoverished backgrounds….

* Further, the theory holds, finding ways to reduce stress in the home and school environment could improve children's well being and allow them to be more successful academically.”

Biodevelopmental Model

The Center on the Developing Child 's Model of "How Early Experiences Get Into the Body"



http://developingchild.harvard.edu/resources/

Applying this to work with children and families now

Worksheet

Summary

* Described key elements of LCT-SDOH
* Application of LCT-SDOH to work with and on behalf of children with developmental disabilities and their families
* Defined "children with special health care needs" (CSHCN)
* Described how child well-being is measured
* Considered how poverty affects child health and well-being

Summary

* **Examples of disparities in child health and well-being**
* **Discussed the impact of social stressors and difficult life circumstances on the children and families we serve and on our work with them**
* **Outlined an approach to respond to families affected by stressors; suggest supportive strategies**