THE NATIONAL CHILDREN'S STUDY

HEALTH GROWTH ENVIRONMENT

The NCS Health Measurement Network

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NCS Metadata Workshop

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NCS-HMN Collaborators

- Neal Halfon, Will Nicholas (UCLA)
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National Academy of Sciences Review of the NCS Protocol: Critique

"The research plan does not specify any particular model or models to guide decisions on which conditions and potential causal factors are chosen for study, the timing of data collection points, the types of data to be collected, and the overall analytical approach."

NAS Review of the National Children's Study Research Plan (2008)

National Academy of Sciences Review of the NCS Protocol: Recommendation

"The NCS should clearly define the key constructs of child health and development and more fully develop a conceptual framework for understanding child health and development over the course of infancy, childhood, and adolescence."

NAS Review of the National Children's Study Research Plan (2008)

The NCS Health Measurement Network

MISSION

The NCS Health Measurement Network will harness the collective intelligence of NCS affiliated scientists to review, develop, validate, and continuously improve theoretically derived, multi-modal and efficiently administrable measures of children's health and development from preconception to the transition to adulthood.

Year 1 (Oct 2011 – Sept 2012) Aims

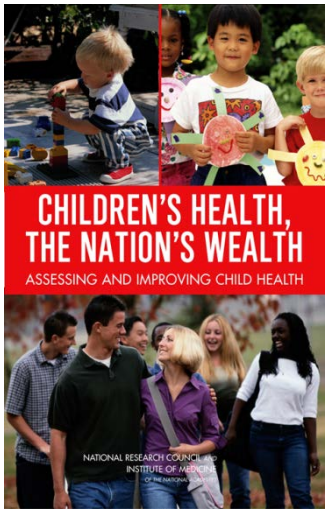
- Develop network design and organizational structure
- Create a theoretical model of child health
- Develop a typology of health domains and prioritize these for measure development
- Conduct field tests of NIH PROMIS among women and NIH Toolbox among children and women
- Prepare for launch of instrument measure development in year 2 and beyond

Metadata Challenges

- Model of health
- Multi-modal assessment and profiles
- Trajectories and linkage

(1) Model of Health
IOM Definition of Children's Health

- **Health conditions**: disorders or illnesses
- **Function**: execution of tasks and participation in desired activities
- **Health potential**: development of assets and positive aspects of health, such as competence, capacity, and developmental potential



Typology Components

Health Dimensions

Typology

- Biological → ICD & ICF
- Functioning → ICF & PROMIS
- Experiential → ICF & PROMIS
- Potential

Vision as an Example

Health Dimensions	Typology
Biological Function	Visual Acuity
Self Functioning	Visual Function Visual Symptoms
Experiential	
Potential	

Physical Fitness as an Example

Health Dimensions	Typology
Biological Function	Cardiorespiratory Fitness
Self Functioning	Physical Function Vitality
Experiential	
Potential	Bone mass Muscular reserve

Typology, Taxonomy/Classifications, and Ontology

- Typology
  - Set of concepts that are clustered by similar features into particular types
- Taxonomy/Classification
  - Classification based on concept identities as well as structure and relationships between concepts
    - Families, whole-part, parent-child
- Ontology
  - Controlled vocabulary of well-defined terms with specific relationships to terms that are created as a way to express data and test hypotheses

(2) Multi-modal Assessment and Health Patterns ("Profiles")

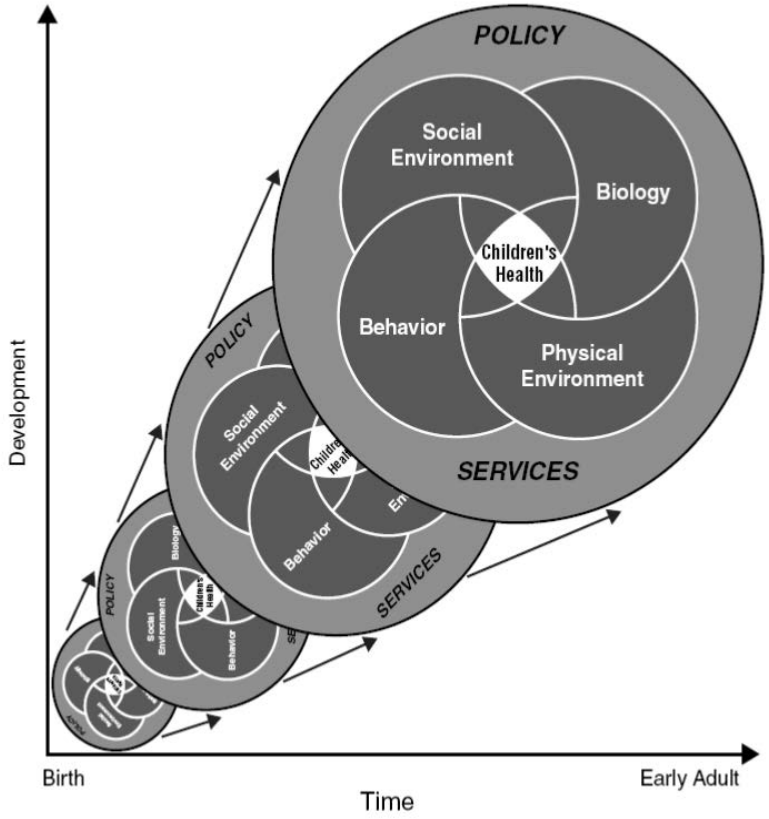
- Same health concept will be measured multiple ways
  - Bio-specimens, device-enabled, observation, person-reported
- For same concept, modalities will change with developmental stage
- Patterns of health will be formed to represent health across multiple domains and modalities

(3) Trajectories

Health and development

- Do not occur randomly;
- Are affected by the prior patterns;
- Future outcomes are influenced by earlier configurations.

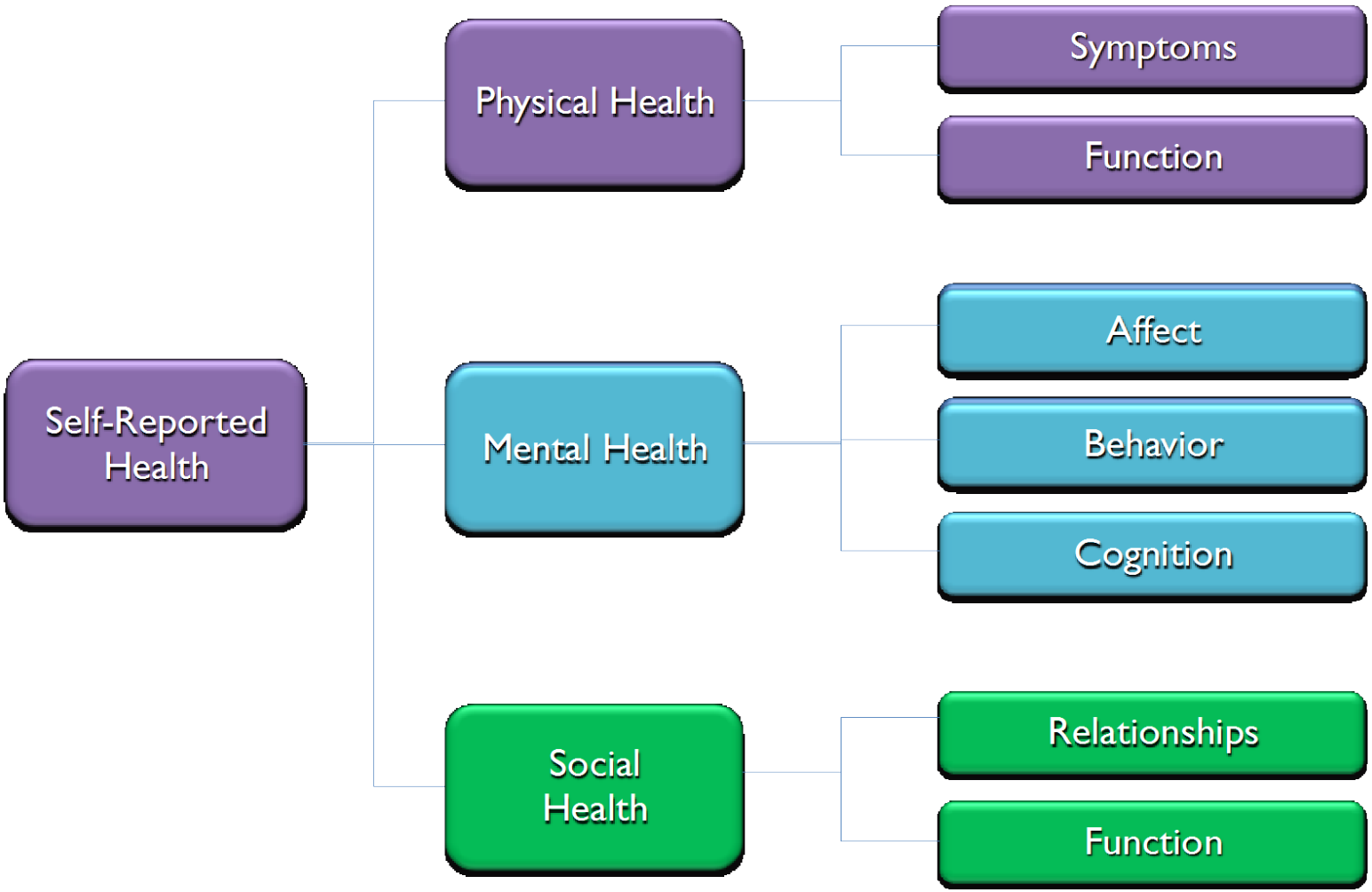
Data collected at discrete time points.
Need to combine to form health measures



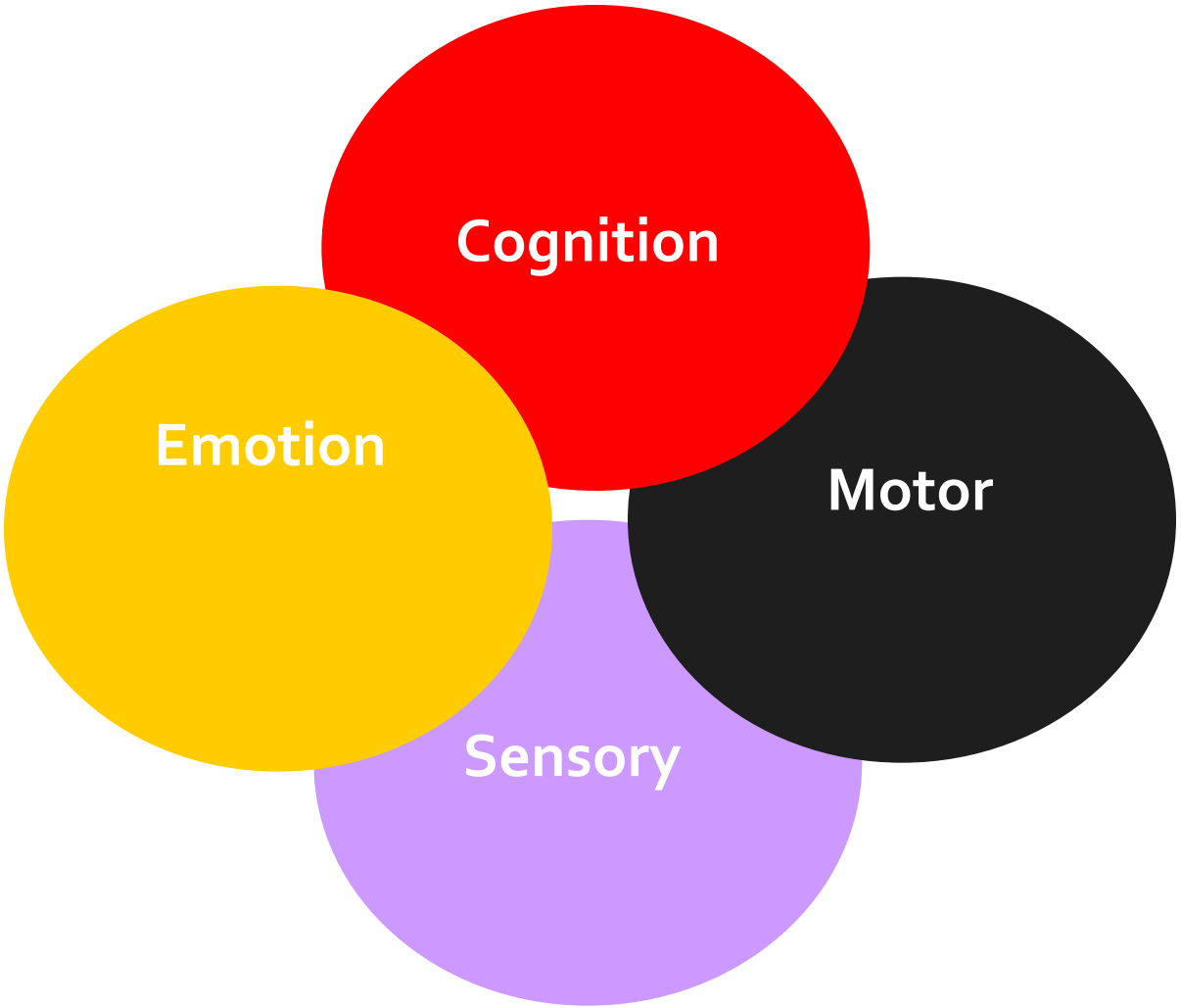
Multi-modal assessment +
Trajectories +
Developmental change =>

<u>The Challenge of Linkage</u>

PROMIS Health Framework



NIH Toolbox Domains



NCS Rosetta Stones

- A common language is needed as a starting point (typology and terminologies)
- Harmonization of all measures to typology
- Statistical linkage to a common metric when possible

Thank you

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