PCORI Workshop on Methodologic Challenges in Intellectual and Developmental Disabilities Research

Via GoToWebinar

March 15, 2021, 1:00-5:30 PM EDT

pcori®
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Housekeeping

- Please note that today's webinar is being recorded for posting on PCORI's website.
- Members of the public are invited to listen to the teleconference and view the webinar.
- Meeting materials can be found on the PCORI website. The recording of the webinar will also be made available to the public after this event.
- Anyone may submit a question or a comment through the webinar chat function.

Please visit www.pcori.org/events for more information.

Meeting Agenda

Time (PM EST)	Topic	Speaker
1:00-1:15	**Introduction**	Steven Goodman, MD, MHS, PhD; Kara Ayers, PhD
Topic I: Measurement Issues Moderator: Naomi Aronson (PCORI Methodology Committee)		
1:15-1:45	**Talks**	Maureen Durkin, PhD, DrPH; Tracy M. King, MD, MPH
1:45-2:25	**Panel discussion**	Marc J. Tassé, PhD; Ruth Luckasson, J.D.
2:25-2:30		**Break**
Topic 2: Issues In Observational And Interventional Designs (Including Infrastructure Issues & Implementation Science) Moderator: Brian Mittman (PCORI Methodology Committee)		
2:30-3:00	**Talks**	David Mandell, ScD; Luther G Kalb, PhD
3:00-3:40	**Panel discussion**	Daniele Fallin, PhD; Danny van Leeuwen, MPH, RN, CPHQ
3:40-3:50		**Break**
Topic 3: Heterogeneity (Of Conditions, Treatments, And Effects, Including Disparities) Moderator: Cindy Girman (PCORI Methodology Committee)		
3:50-4:20	**Talks**	Sarabeth Broder-Fingert, MD, MPH; Tawara D. Goode, MA
4:20-5:00	**Panel discussion**	Elizabeth Stuart, PhD; Bradley L Schlaggar, MD, PhD; Melissa A. Parisi, MD, PhD
5:00-5:15	**Summary and wrap-up**	

Introduction

Steven Goodman, MD, MHS, PhD

Associate Dean for Clinical and Translational Research

Professor of Epidemiology & Population Health, and Medicine

Stanford University School of Medicine

Chair, PCORI Methodology Committee

PCORI's Reuthorization Law

H.R.1865 - Further Consolidated Appropriations Act, 2020

(d) Identification of Research Priorities.--Subsection (d)(1)(A) of section 1181 of the Social Security Act (42 U.S.C. 1320e) is amended by adding at the end the following:

*"**Such national priorities shall include research with respect to intellectual and developmental disabilities** and maternal mortality. Such priorities should reflect a balance between long-term priorities and short-term priorities, and be responsive to changes in medical evidence and in health care treatments.".*

[Emphasis added.]

Opening Remarks

Kara Ayers, PhD

Associate Director, UCEDD, Division of Developmental and Behavioral Pediatrics

Assistant Professor, Cincinnati Children’s Hospital Medical Center

Board of Governors Member, PCORI

Topic 1: Measurement Issues

Speakers

Maureen Durkin, PhD, DrPH

Evan and Marion Helfaer Professor of Public Health and Chair, Department of Population Health Sciences

University of Wisconsin School of Medicine and Public Health

Tracy M. King, MD, MPH

Medical Officer, Intellectual and Developmental Disabilities Branch (IDDB)

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institutes of Health (NIH)

Definition and Measurement Issues in Intellectual and Developmental Disabilities (IDD) Research

Maureen Durkin, PhD, DrPH

PCORI Workshop Webinar:

Methodologic Challenges in Intellectual and Developmental Disabilities Research

March 15, 2021

WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON

Population
Health
Sciences

Issues

- Definitions and concepts of disability: toward an international consensus
- Intersection of health disparities: disability, race, ethnicity, poverty, gender, …
- What outcomes and whose perspectives matter in comparative effectiveness studies of IDD interventions?
- Informed consent
- Prevention --- not of people with IDD, but of the causes of disability, disparities
- Re-framing to focus on abilities, positive outcomes, acceptance of diversity
- Importance of a life-course perspective and challenges in measuring change
- Etiologic and phenotypic heterogeneity
- Validation and applicability of outcome measures for diverse people with IDD
- Emerging technologies: opportunities and challenges for measuring meaningful IDD outcomes

Definition of IDD

- Limitations in functioning resulting from disorders or injuries affecting the developing nervous system, onset early in life.
- Manifest as delays in reaching developmental milestones, such as walking or talking, or as limited functioning in cognition, motor performance, vision, hearing, communication, speech, and behavior.
- Broad umbrella affecting ~18% of children in the U.S., life-course impacts
- Etiologic and phenotypic heterogeneity (intellectual disability, cerebral palsy, epilepsy, autism spectrum disorder, ADHD, and speech, language, vision, hearing and other disabilities)
- Etiology is often unknown; Co-occurrence of disabilities very common

Two Intellectual Traditions Have Shaped Population Health Policies and Outcome Measures Relevant to IDD Research

Utilitarianism	**Social Contract Theory**
Greatest good for the greatest number.	**Greatest benefit to the least advantaged.**
Cost effectiveness: How can we allocate limited resources to maximize happiness and wellbeing for the population overall?	Under a veil of ignorance, people would choose policies that benefit those with disabilities and complex needs.
A society with high inequality and suffering of a minority, including people with disabilities, may be acceptable if it produces maximum benefit for the population overall.	A just society is one that rational, self-interested individuals would pick to gain protection, in exchange for some loss of freedom.
Outcomes of interest: Disability and Quality Adjusted Life Years (DALYs, QALYs)	Outcomes of interest: Health equity/disparities; levels of functioning, participation & supports needed

IDD and Health Disparities

Some important distinctions:

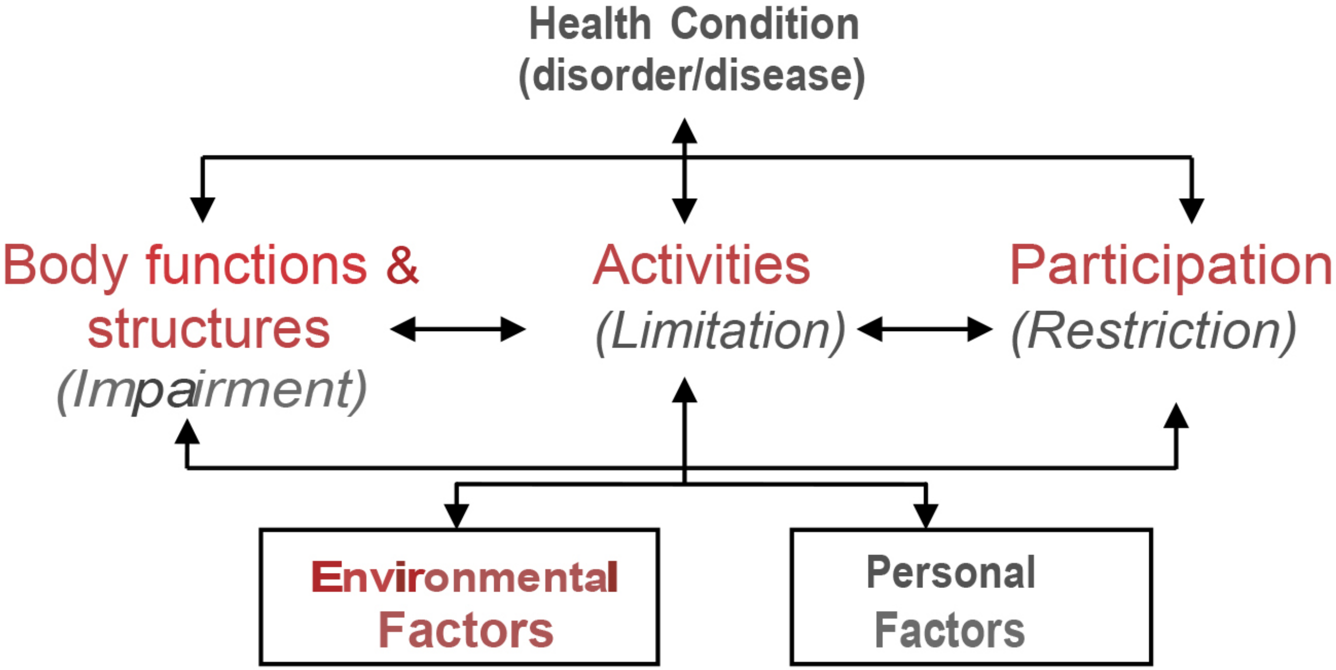
  - *Disability* and *health*: to have a disability does not necessarily imply poor health
  - Health *Inequalities* vs. *inequities* or disparities
- IDD as a health disparity group – health disparities often result from injustices and inequities in access to care, exposure to risk factors, stigma
- Yet many IDD conditions lead to complex medical needs and illnesses not attributable to injustices
- This is a challenge and a complexity in IDD intervention and outcomes research.

ICF: Interaction of Concepts

ICF

International
Classification of
Functioning,
Disability
and
Health

World Health Organization
Geneva



Health Condition
(disorder/disease)

Body functions & structures
(Impairment)

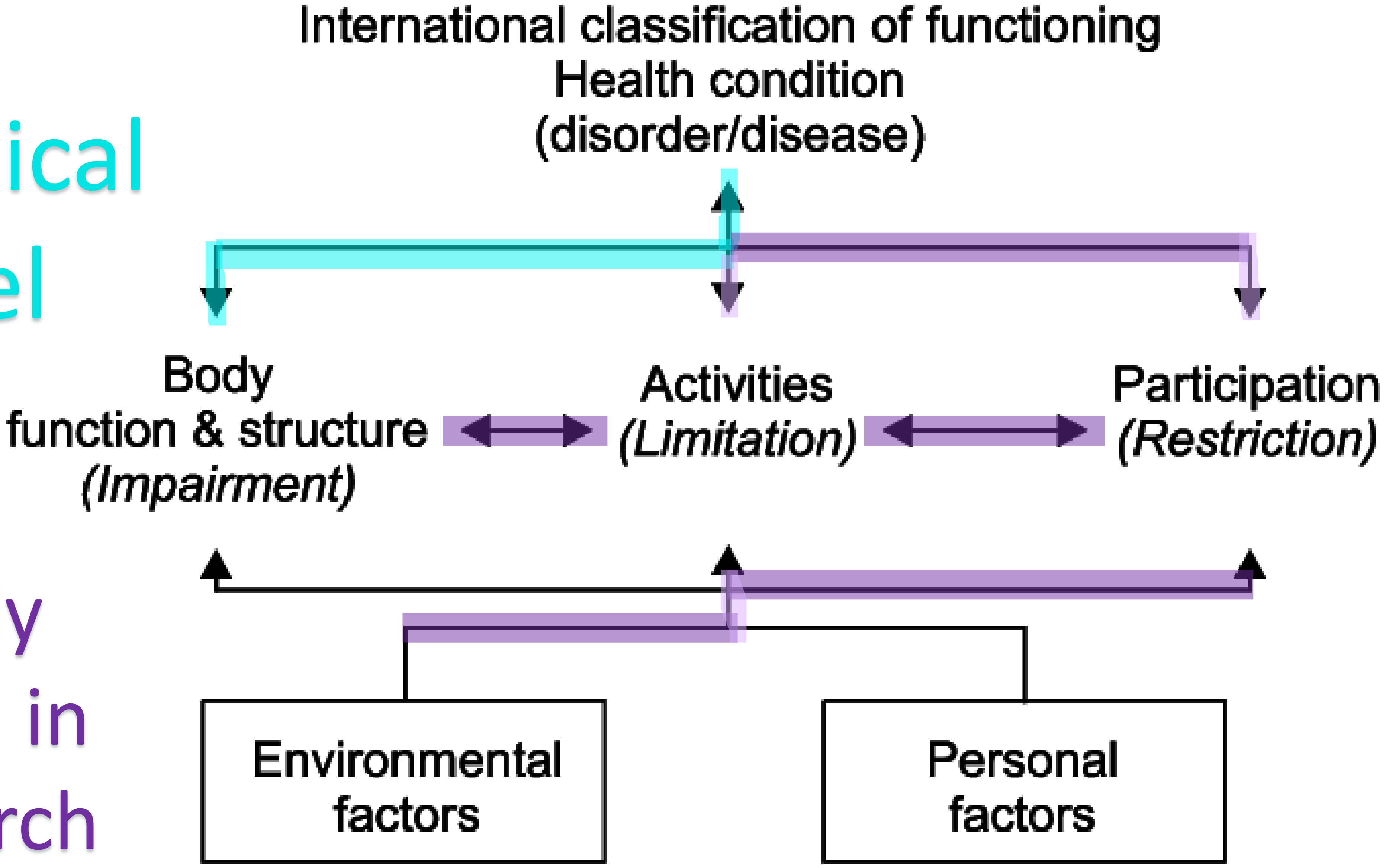
Activities
(Limitation)

Participation
(Restriction)

Environmental Factors

Personal Factors

Biomedical Model



International classification of functioning
Health condition
(disorder/disease)

Body
function & structure
(Impairment)

Activities
(Limitation)

Participation
(Restriction)

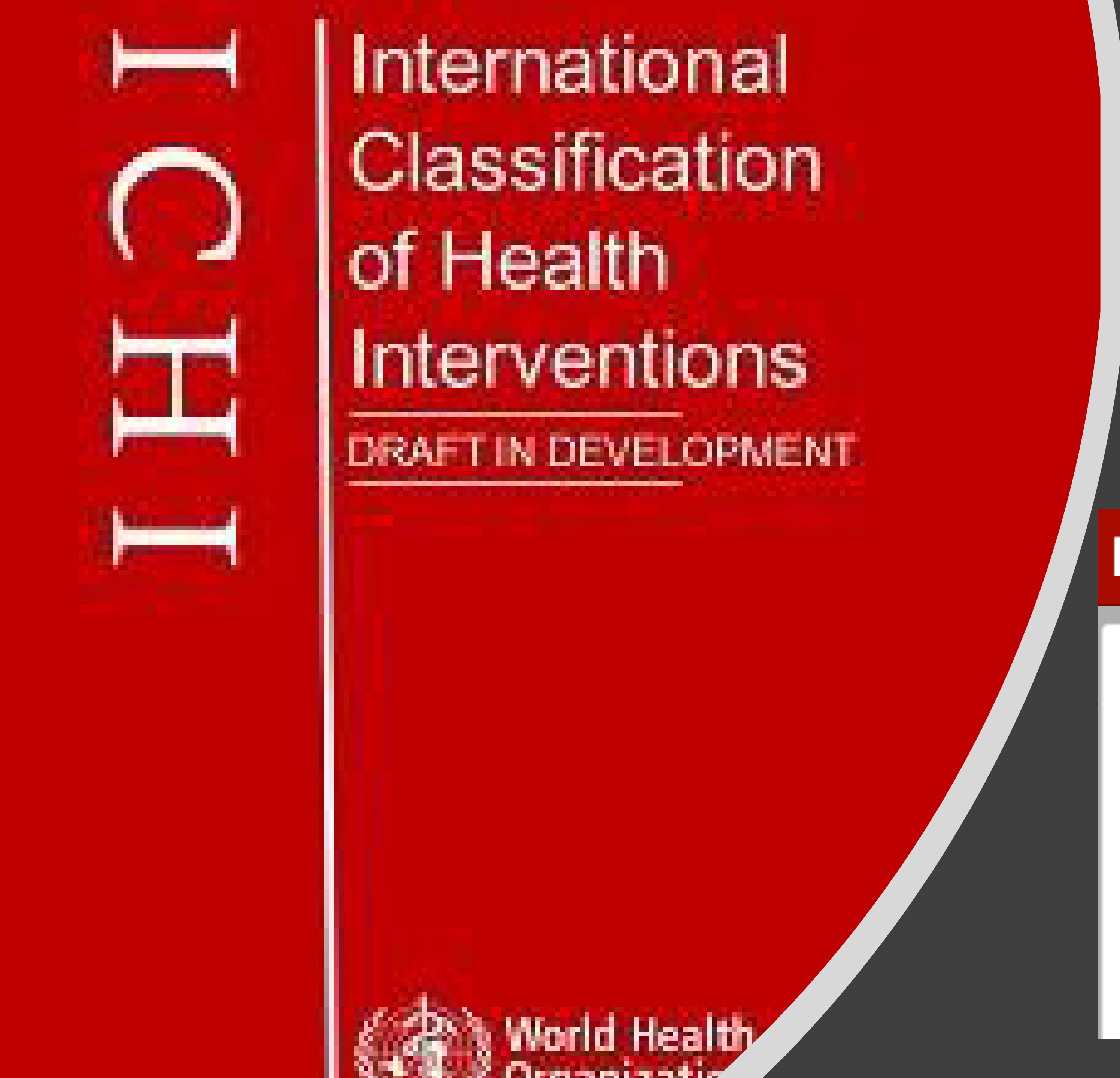
Environmental factors

Personal factors

Relatively neglected in IDD research

Examples of Outcome Measures, Tools and Intervention Targets in IDD Research

Body Structures & Functions	Activities	Participation	Environmental Factors	Personal Behaviors
Neuroimaging	Adaptive Behavior Scales	Child Assessment of Participation and Enjoyment	Built Environment	Physical Activity
EEG	Gross Motor Functioning Classification Scale		Social Determinants of Health	Diet
Evoked Responses	Communication Function Classification System	FOCUS Communication Scale	Inclusive Healthcare	Preventive Care
Eye Tracking	Autism Classification System of Functioning: Social Communication	Child and Adolescent Scale of Participation	Inclusive Social, Economic & Education Policies	Substance Use
IQ	Activities of Daily Living	Child Participation Assessment Tool	Social Supports	
Other Clinical Tests and Biomarkers	Quality of Life measures		Human Rights Policies	
			Stigma	



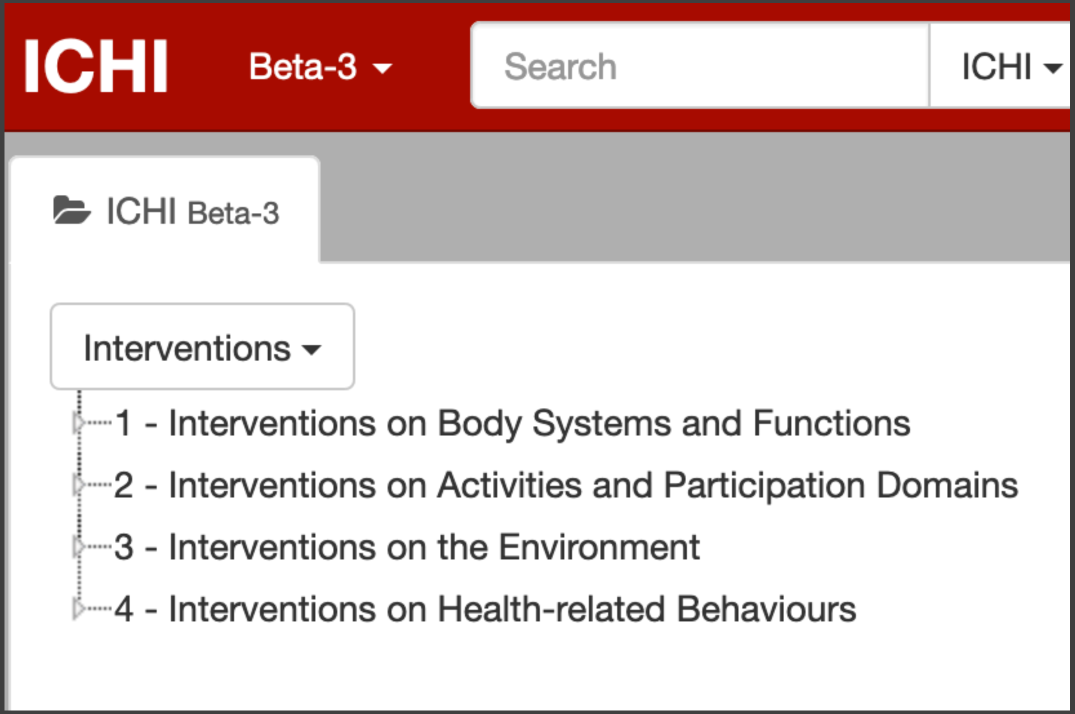
ICHI

International Classification of Health Interventions

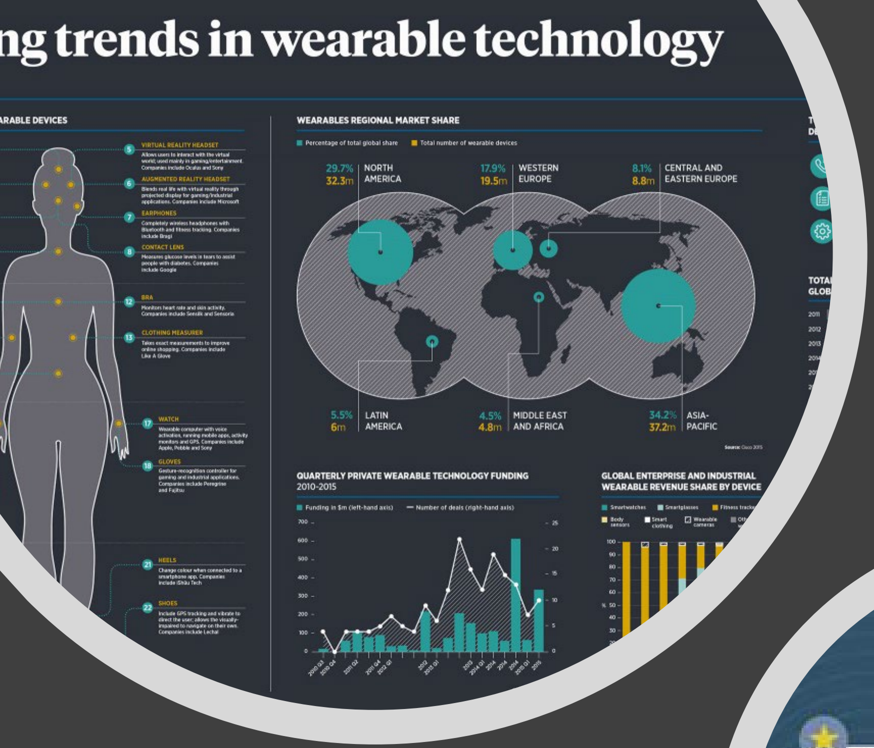
DRAFT IN DEVELOPMENT

World Health

Aligned with WHO's International Classification of Functioning, Disability and Health (ICF)



- 1 - Interventions on Body Systems and Functions
- 2 - Interventions on Activities and Participation Domains
- 3 - Interventions on the Environment
- 4 - Interventions on Health-related Behaviours



Emerging Technologies

Conclusions

- Patient Centered Outcomes Research on IDD and with individuals affected by IDD necessitates a human rights perspective on disability
- Health disparities are prevalent and complex in IDD
- Biomedical outcomes are *of utmost importance* in research to improve outcomes for individuals with IDD, *but not sufficient*
- The ICF model calls for greater attention to outcomes that matter over the life course and to the multiple determinants of those outcomes
- Emerging technologies should be harnessed to provide comprehensive and meaningful measures for patient centered IDD outcomes research, though they pose privacy and equity concerns.

Selected References

- Gross S, Lollar DJ, Campbell VA, Chamie M, Disability and disability-adjusted life years: not the same. *Public Health Reports*, 2009; 124:197-202.
- Hidecker MJC, Cunningham BJ, Thomas-Stonell, Oddson B, Rosenbaum P, Validity of the Communication Function Classification System for use with preschool children with communication disorders. *Developmental Medicine and Child Neurology,* 2017; 59:526–530.
- Khoshmanesh F, Thurgood P, Pirogova E, Nahavandi S, Baratchi S, Wearable sensors: at the frontier of personalised health monitoring, smart prosthetics and assistive technologies. *Biosens Bioelectron* 2021;176:112946.
- Krahn GL, Walker DK, Correa-de-Araujo R, Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 2015; 105(S2):S198-206.
- Rainey L, van Nispen R, van der Zee C, van Rens G, Measurement properties of questionnaires assessing participation in children and adolescents with a disability: a systematic review. *Quality of Life Research*, 2014; 23(10):2793-2808 .
- Rawls J, *A Theory of Justice*. Belknap Press, 1971.
- Rosenbaum P, How do we know if interventions in developmental disability are effective? *Developmental Medicine and Child Neurology,* 2020; 62(12):1344.
- Zablotsky B, Black L, Maenner M, et al. Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics*. 2019;144(4):e20190811.

Methodological Issues in Studies of Intellectual and Developmental Disabilities

PCORI Methodology Committee Workshop

March 15, 2021

NIH *Eunice Kennedy Shriver* National Institute of Child Health and Human Development

Tracy M. King, MD, MPH

Eunice Kennedy Shriver National Institute of Child Health and Human Development

Disclaimer

The views expressed in this presentation represent the opinions of the speaker and not necessarily those of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development.

Key questions

- **What** needs to be measured?
  - Risk / Exposures
  - Interventions
  - Outcomes
- **How** do we measure it?
  - What tools?
  - Whose perspective?
  - Compared to what/whom?

- **How well** do we measure it?
  - Accuracy and precision across:
    - Ages
    - Developmental levels
    - Cultures and communities
- **Does it matter**?
  - Ease of measurement ***vs*** meaningfulness
  - Positive outcomes ***vs*** absence of negative outcomes

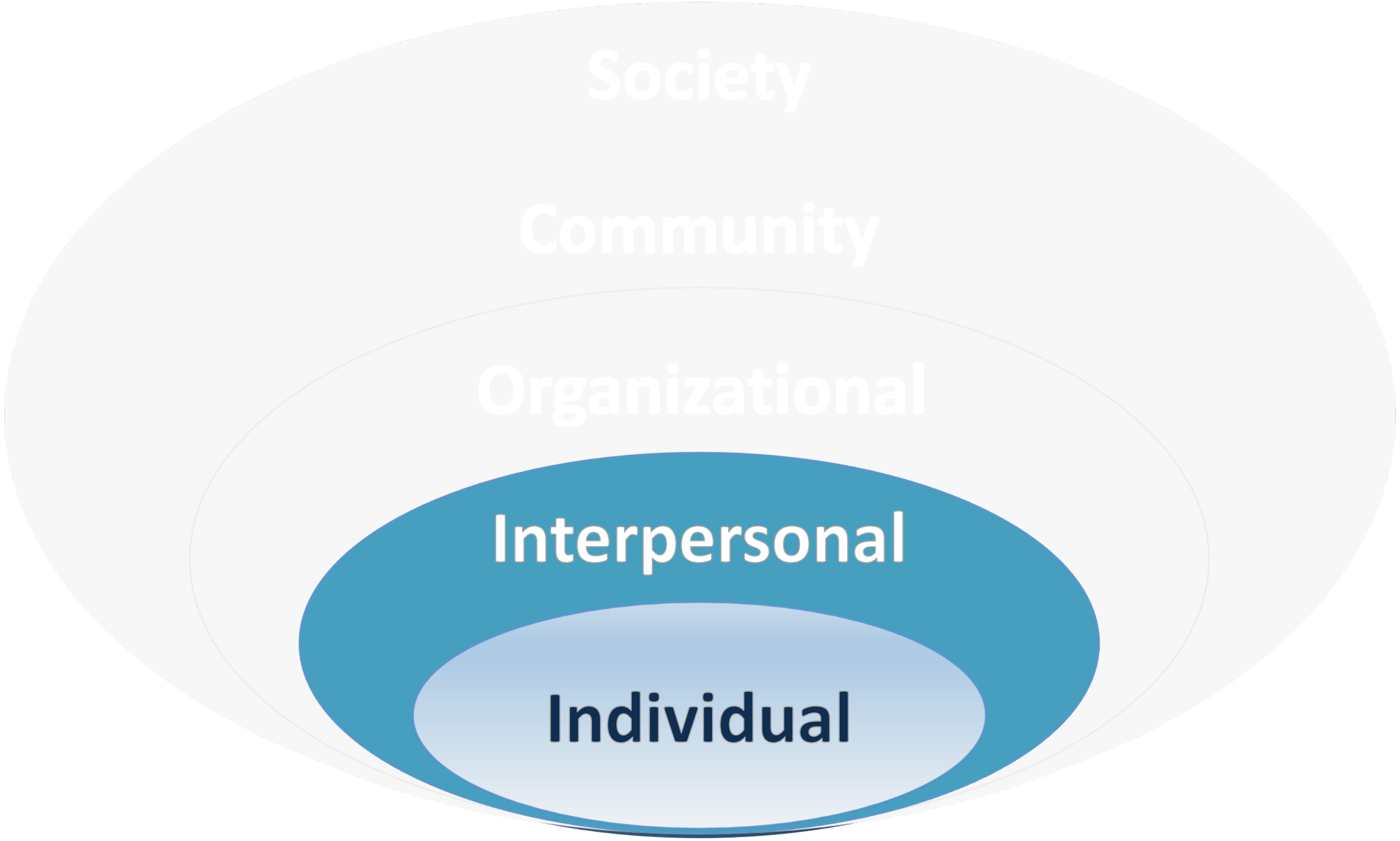
Key questions

- **What** needs to be measured?
  - Risk / Exposures
  - Interventions
  - Outcomes
- **How** do we measure it?
  - What tools?
  - Whose perspective?
  - Compared to what/whom?
- **How well** do we measure it?
  - Accuracy and precision across:
    - Ages
    - Developmental levels
    - Cultures and communities
- **Does it matter**?
  - Ease of measurement ***vs*** meaningfulness
  - Positive outcomes ***vs*** absence of negative outcomes

What
needs to be measured?

EXPOSURES

Exposures occur at Multiple Levels



Society

Community

Organizational

Interpersonal

Individual

Exposures occur at Multiple Levels

<u>What</u> needs to be measured?

<u>EXPOSURES</u>

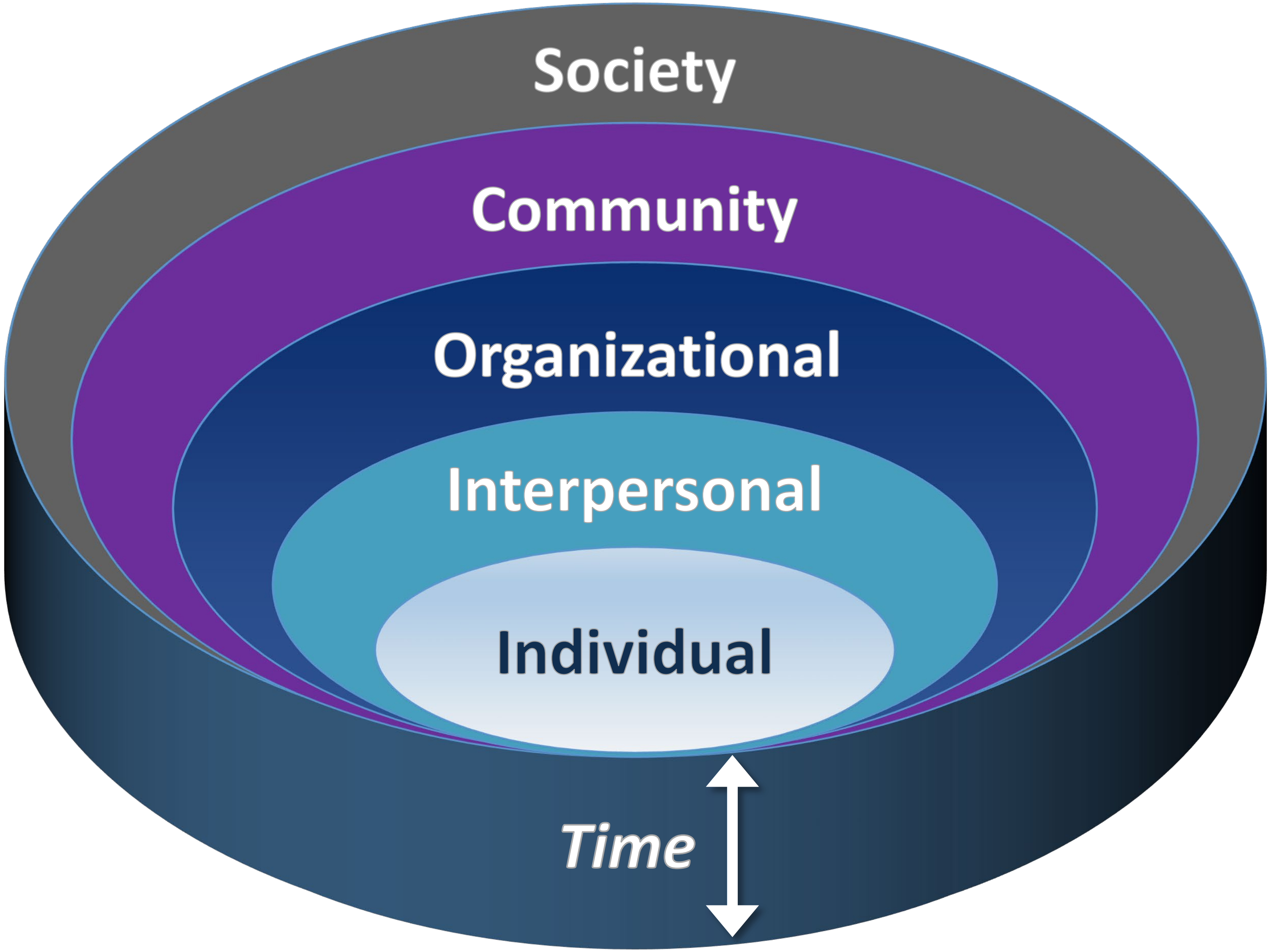
Adapted from https://www.cdc.gov/violenceprevention/about/social-ecologicalmodel.html

What needs to be measured?

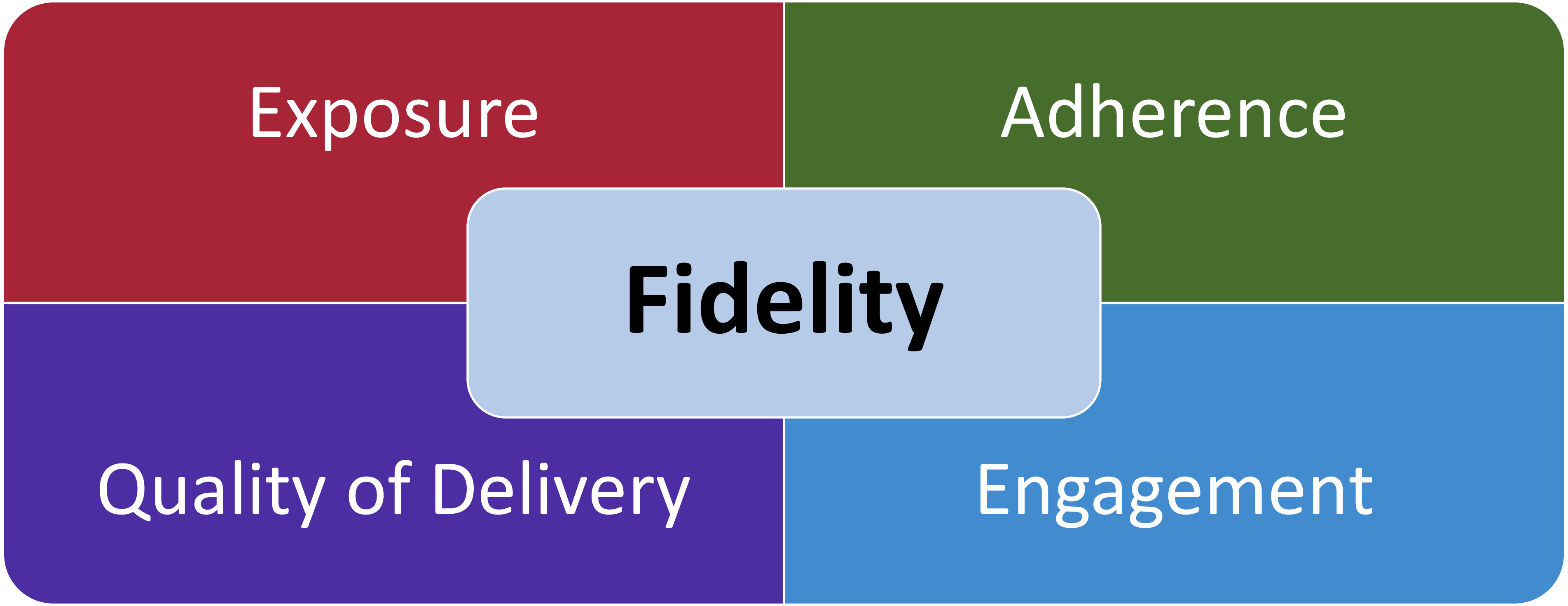
EXPOSURES

Adapted from https://www.cdc.gov/violenceprevention/about/social-ecologicalmodel.html

Exposures occur at Multiple Levels



What needs to be measured? ***INTERVENTIONS***



Exposure

Adherence

Fidelity

Quality of Delivery

Engagement

Source: Wisconsin RtI Center; https://slideplayer.com/slide/3892245/

Key questions

- What needs to be measured?
    - Risk / Exposures
    - Interventions
    - Outcomes
- **How** do we measure it?
    - What tools?
    - Whose perspective?
    - Compared to what/whom?
- **How well** do we measure it?
    - Accuracy and precision across:
        - Ages
        - Developmental levels
        - Cultures and communities
- **Does it matter**?
    - Ease of measurement ***vs*** meaningfulness
    - Positive outcomes ***vs*** absence of negative outcomes

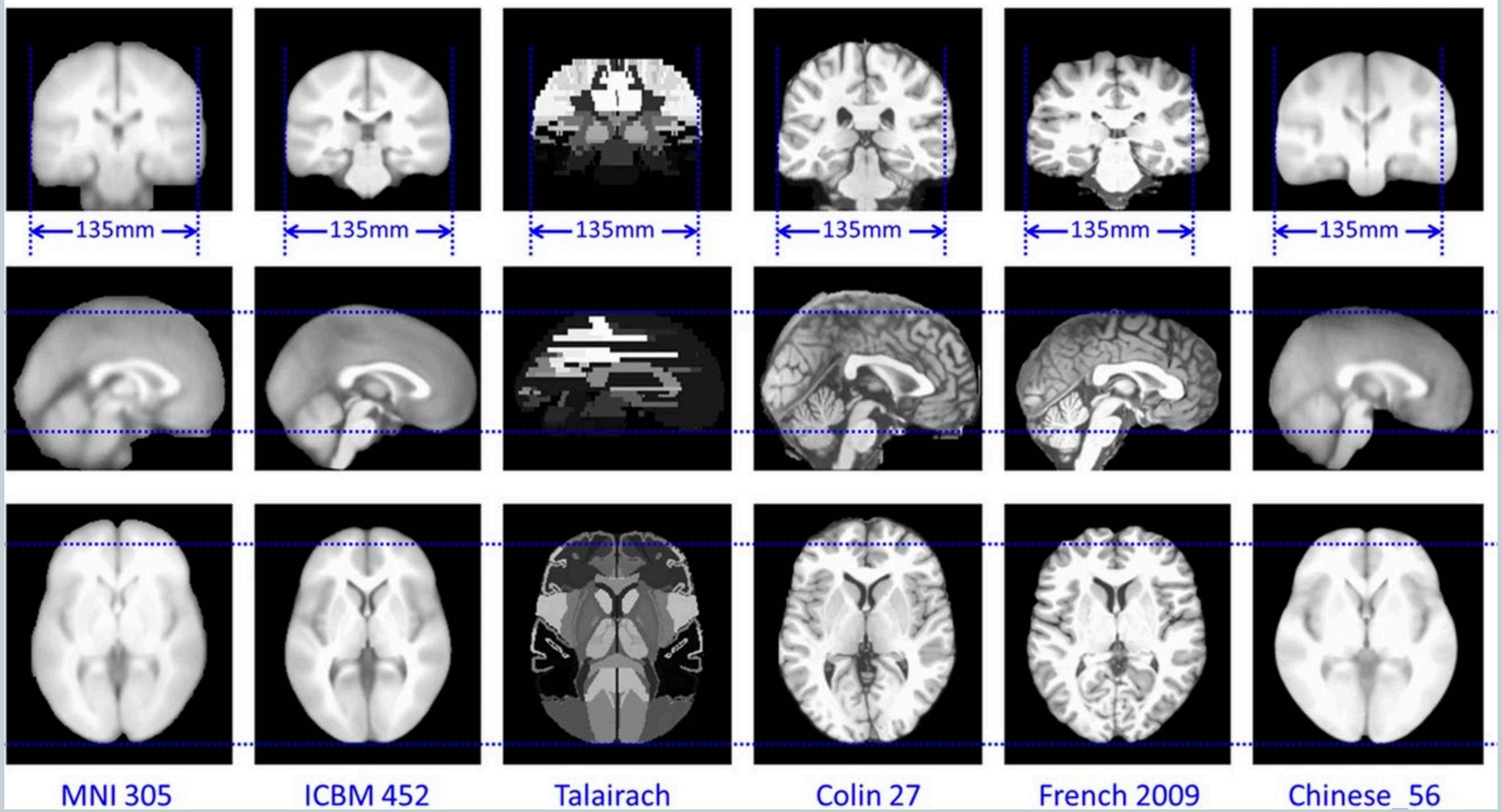
How do we measure outcomes?

- What tools?
  - Floor effects seen with many standard neuropsychological tests
  - Some instruments / approaches may systematically exclude certain groups
    - Example: MRI
- Whose perspective?
  - Self report vs caregiver report
  - Caregiver report vs caregiver proxy report
  - Are all people who are capable of self report being offered the opportunity to self report?

How do we measure outcomes?

- Compared to what/whom?
  - “normative” or “reference” samples
  - Cultural differences
    - Outcomes don’t hold the same importance / value to all people
  - Does your condition impact your ability to self-report?
    - Does this impact change with time / level of symptom control?
    - Implications for studies using pre/post designs

CHALLENGE: DIVERSITY
CHINESE BRAIN ATLAS COMPARISON



Liang, P., Shi, L., Chen, N. *et al.* Construction of brain atlases based on a multi-center MRI dataset of 2020 Chinese adults. *Sci Rep* **5,** 18216 (2016). https://doi.org/10.1038/srep18216

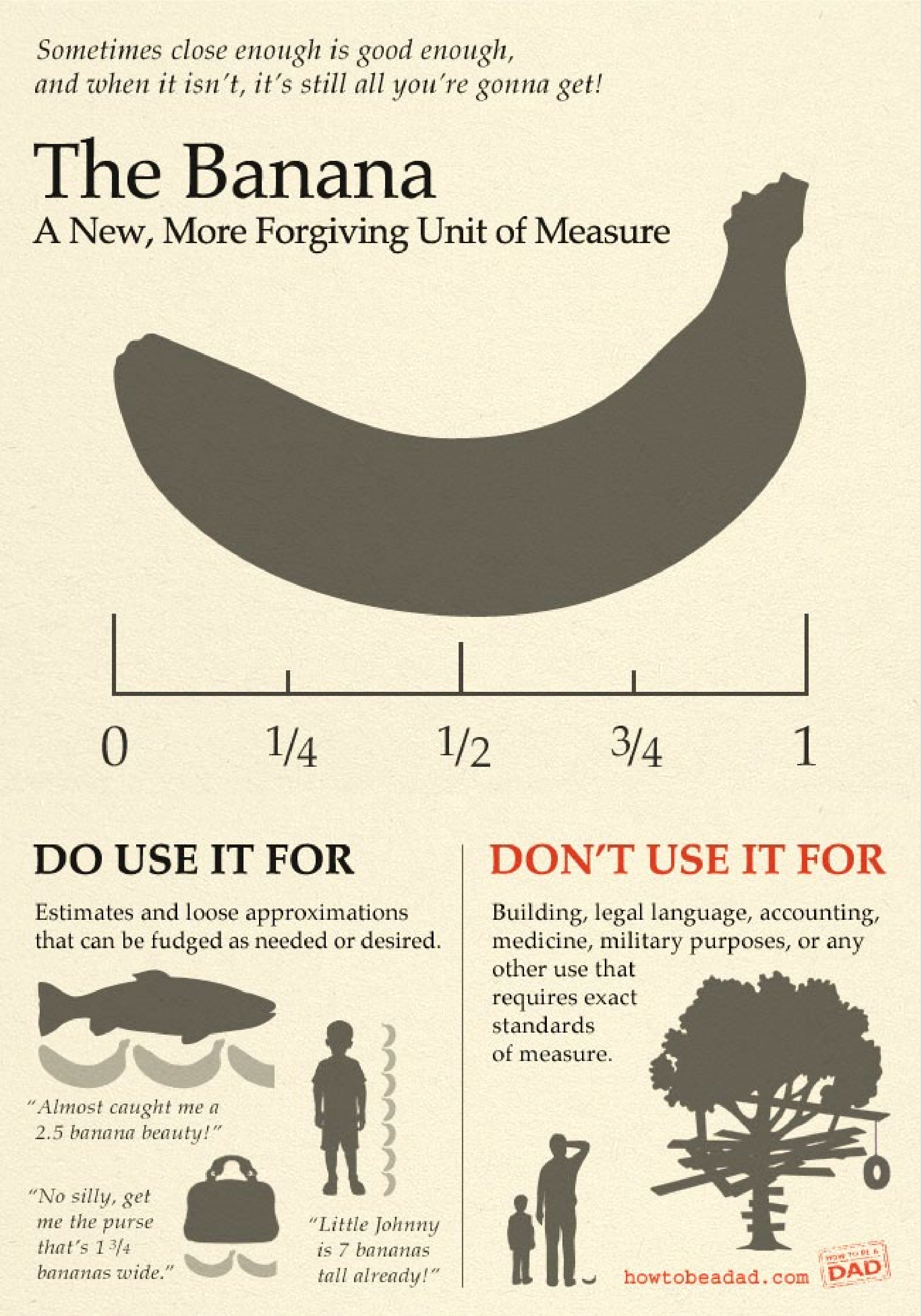
Slide courtesy of Susan Bookheimer, PhD

How do we measure outcomes?

- Compared to what/whom?
  - “normative” or “reference” samples
  - Personal preferences / cultural differences
    - Outcomes don’t hold the same importance / value to all people
  - Does your condition impact your ability to self-report?
    - Does this impact change with time / level of symptom control?
    - Implications for studies using pre/post designs

How *well* do we measure outcomes?

- Accuracy and precision across:
  - Ages
  - Developmental levels – have measures been validated in IDD populations?
    - Role of heterogeneity – stay tuned
  - Cultures and communities
- Technology – may address some challenges, but may introduce others
  - Mobile technologies / wearables – do they perform the same way in IDD as typically developing populations?
  - AI algorithms – what samples are they being “trained” on?
- Does not only apply to outcomes
  - Are we measuring contextual (family, community, society) factors accurately and precisely?



Sometimes close enough is good enough,
and when it isn't, it's still all you're gonna get!

The Banana

A New, More Forgiving Unit of Measure

DO USE IT FOR

Estimates and loose approximations that can be fudged as needed or desired.

"Almost caught me a 2.5 banana beauty!"

"No silly, get me the purse that's 1 3/4 bananas wide."

"Little Johnny is 7 bananas tall already!"

DON'T USE IT FOR

Building, legal language, accounting, medicine, military purposes, or any other use that requires exact standards of measure.

howtobeadad.com

http://web.archive.org/web/20120829100716/http://www.howtobeadad.com/tag/banana-added-for-scale

How *well* do we measure outcomes?

- Accuracy and precision across:
  - Ages
  - Developmental levels – have measures been validated in IDD populations?
  - Cultures and communities
- Technology – may address some challenges, but may introduce others
  - Mobile technologies / wearables – do they perform the same way in IDD as typically developing populations?
  - AI algorithms – what samples are they being “trained” on?
- Does not only apply to outcomes
  - Are we measuring contextual (family, community, society) factors accurately and precisely?

Does it matter?

What outcomes *matter* to people with IDD?

- Extremely understudied
- Likely that meaningful outcomes are more challenging to define and measure than those in most common use
- Critical area for future efforts in patient-centered outcomes research involving persons with IDD

Key questions

- What needs to be measured?
    - Risk / Exposures
    - Interventions
    - Outcomes
- How do we measure it?
    - What tools?
    - Whose perspective?
    - Compared to what/whom?
- How well do we measure it?
    - Accuracy and precision across:
        - Ages
        - Developmental levels
        - Cultures and communities
- **Does it matter**?
    - Ease of measurement ***vs*** meaningfulness
    - Positive outcomes ***vs*** absence of negative outcomes

“Meaningful” outcomes

https://www.youtube.com/watch?v=K9HvnRJT-8A

Positive outcomes *vs* absence of negative outcomes

- Recommendations for many clinical interventions are based on reducing rates of morbidity and mortality

- Many interventions for persons with IDD aim to improve positive outcomes, rather than reduce negative outcomes

  Measurement challenges

  - Benefits may take years to fully accrue
    - Need for innovation in study designs, measure development, analytic approaches
  - Positive outcomes (e.g. “well-being”) have been insufficiently defined and operationalized
    - particularly true for certain groups (children, persons with IDD)

SUMMARY

Multiple challenges and opportunities ahead

- Identifying <u>what</u> needs to be measured
  - Exposures
  - Interventions
  - Outcomes
- Determining <u>how</u> best to measure them
  - Expanding our views of what and how persons with IDD can report <u>for themselves</u>
- Identifying and measuring <u>outcomes that matter</u>

Questions?

tracy.king@nih.gov

Topic 1: Measurement Issues

Panel Discussion

Maureen Durkin, PhD, DrPH

Evan and Marion Helfaer Professor of Public Health and Chair, Department of Population Health Sciences

University of Wisconsin School of Medicine and Public Health

Tracy M. King, MD, MPH

Medical Officer, Intellectual and Developmental Disabilities Branch (IDDB)

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institutes of Health (NIH)

Marc J. Tassé, PhD

Director, Nisonger Center - UCEDD

Professor, Departments of Psychology and Psychiatry

Ohio State University

Ruth Luckasson, J.D.

Distinguished Professor

Chair, Department of Special Education

University of New Mexico

Break

5 minutes

Topic 2: Issues in Observational and Interventional Designs

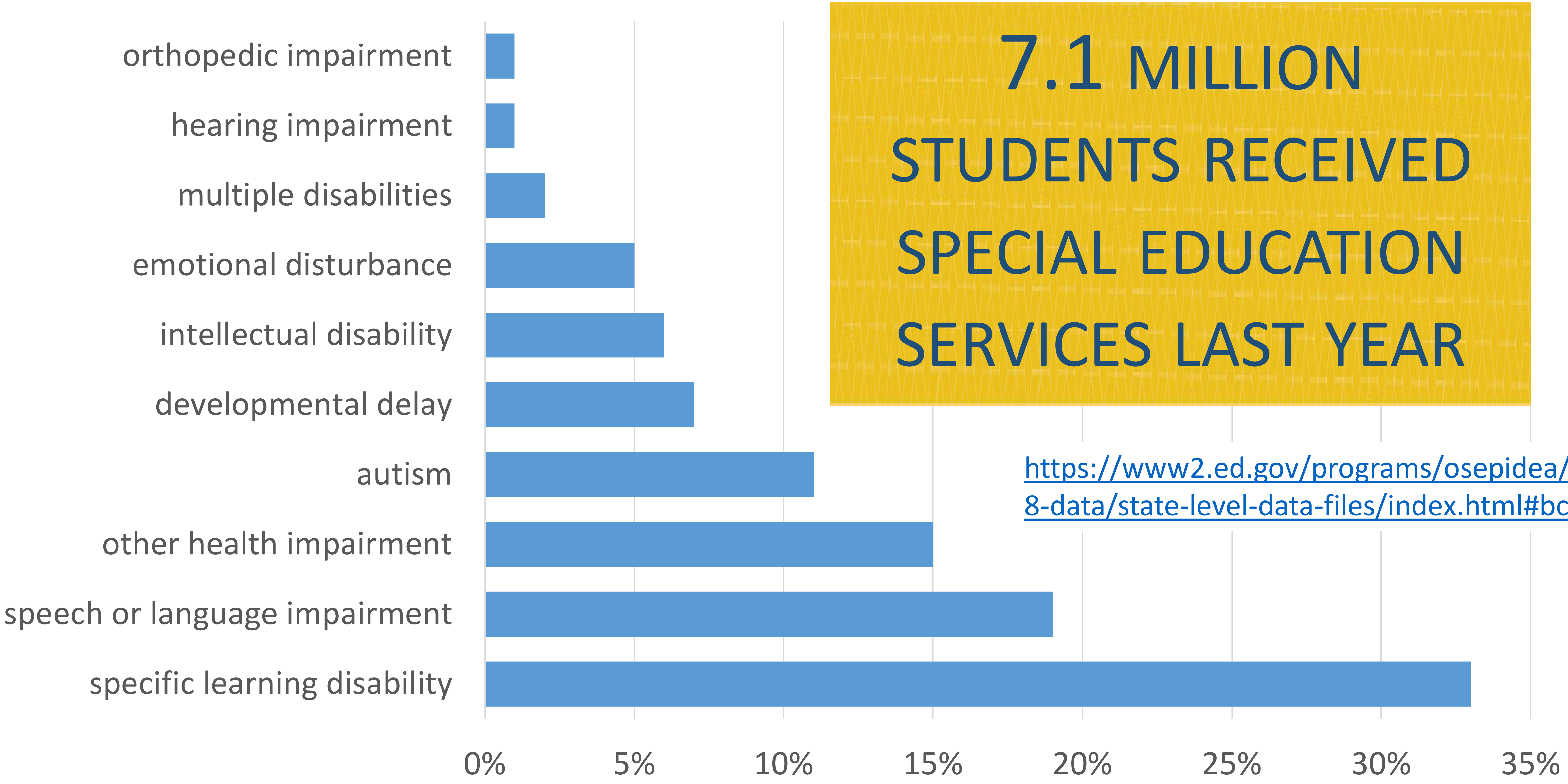
Speakers

David Mandell, ScD
Professor and Director, Penn Center for Mental Health
University of Pennsylvania School of Medicine

Luther G Kalb, PhD
Director of Informatics, Center for Autism and Related Disorders, Department of Neuropsychology
Kennedy Krieger Institute
Assistant Professor, Department of Mental Health
Johns Hopkins Bloomberg School of Public Health

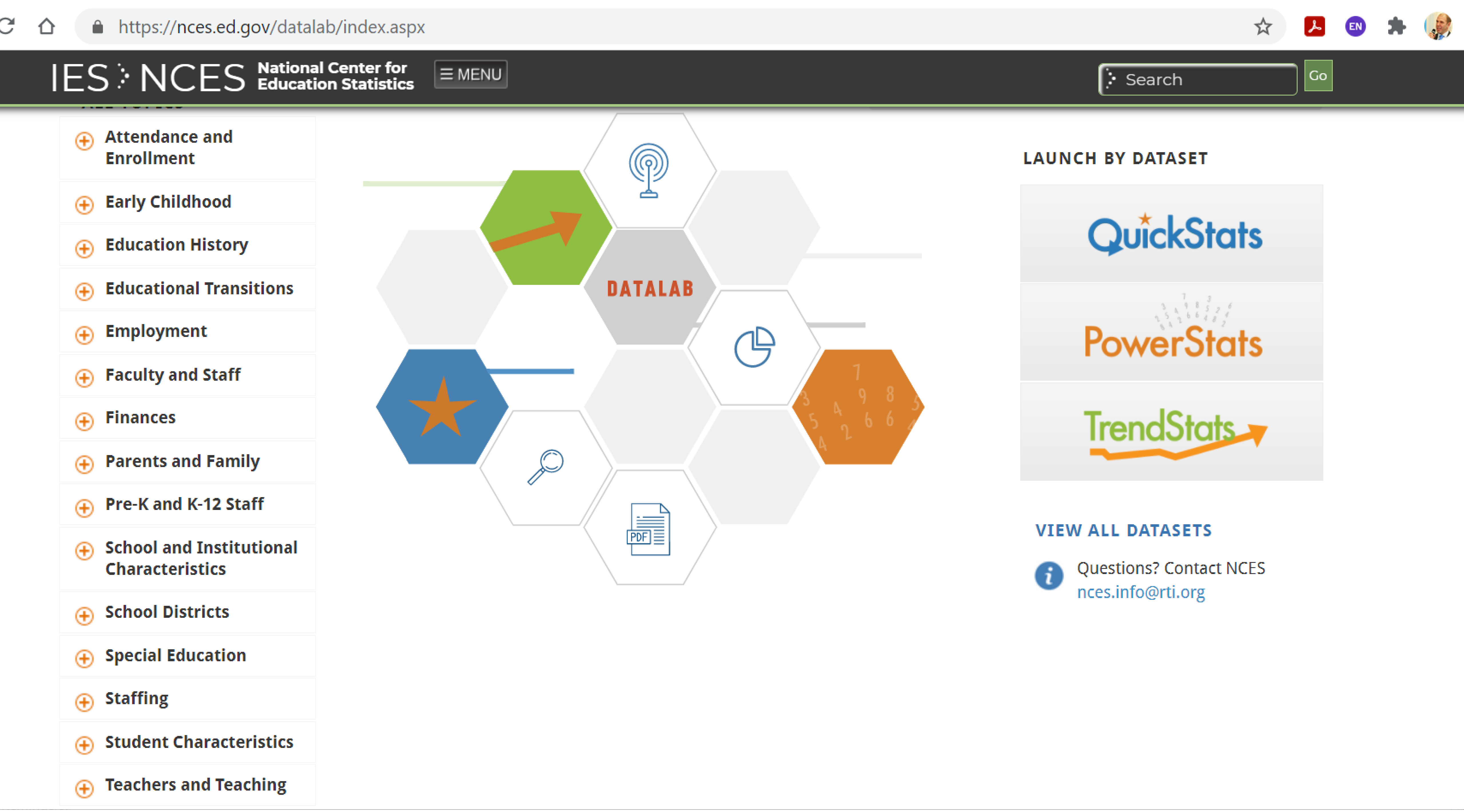
USING ADMINISTRATIVE DATA TO STUDY OUTCOMES IN OBSERVATIONAL AND PRAGMATIC TRIALS

DAVID S. MANDELL & HEATHER J. NUSKE



7.1 MILLION STUDENTS RECEIVED SPECIAL EDUCATION SERVICES LAST YEAR

https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc



Questions? Contact NCES
nces.info@rti.org

WE KNOW A FEW THINGS ABOUT MILLIONS OF CHILDREN

PHENOMENAL COSMIC POWERS!

ITTY BITTY LIVING SPACE.

MEASURED OUTCOMES

- Disciplinary actions
- % time spent in general education settings
- Graduation

- Also many sampled datasets examining educational experiences and outcomes more granularly
  - **Pre-Elementary Education Longitudinal Study (PEELS)**
  - **Early Childhood Longitudinal Study: Birth Cohort (ECLS-B)**
  - **Education Longitudinal Study (ELS)**
  - **High School Longitudinal Study (HSLS)**

NOT ATTACHED TO PARTICULAR INTERVENTIONS

- No information specific to individualized education plans
- No information about services delivered

MANY MORE MILLIONS HAVE HEALTH INSURANCE CLAIMS

- Medicaid
- Optum
- Fair Health
- Anthem

POSSIBLE OUTCOMES

- Hospitalizations and emergency room visits
- HEDIS measures

- No clinical data on outcomes

DETAILED INFORMATION ON SERVICE USE

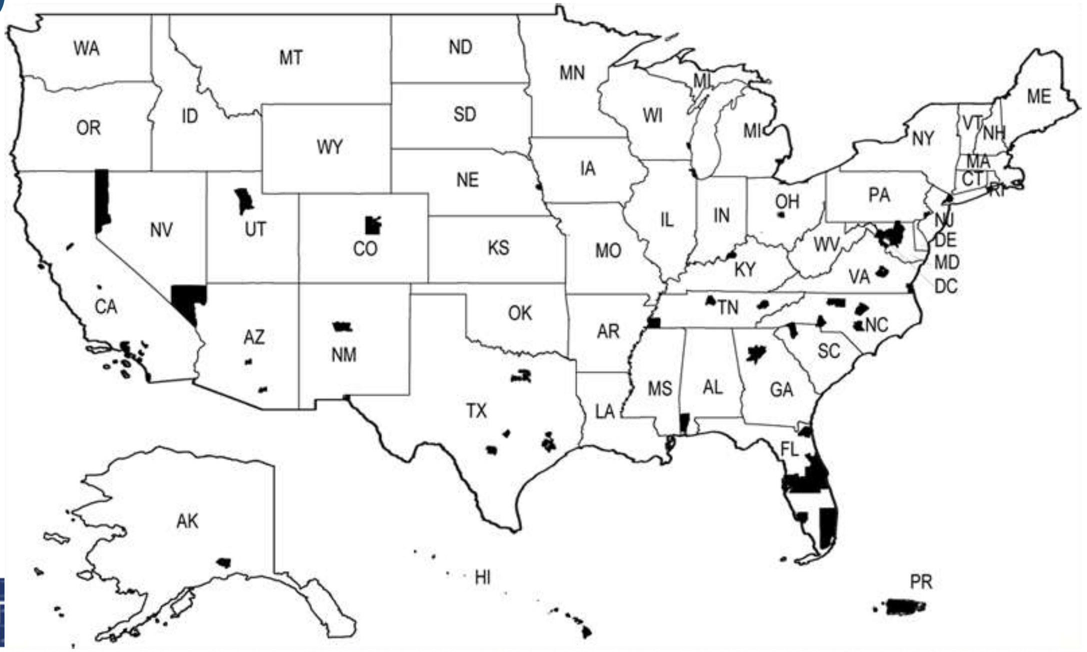
- Medications
- Outpatient services
- Can calculate HEDIS (Healthcare Effectiveness Dataset and Information Set) measures, but none specific to IDD

EXTRAORDINARY OPPORTUNITIES IF WE CAN…

- Merge education and health care claims
- Collect data on education services delivered
- Develop quality measures specific to IDD
- Rethink/develop outcome measures in IDD consistent with others used in pragmatic trials (e.g., PHQ-9, GAD7)

POSSIBILITIES INCLUDE:

- Rethinking connection between HIPAA and FERPA
- Develop registries of participants willing to let us link their data
- Leverage IDEA to require data collection on services delivered
- NCES data collection specific to IDD
- Create school district partnerships



Advancing a Learning Healthcare System in Intellectual and Developmental Disabilities through Clinical Informatics

Luther Kalb, PhD, MHS
Director of Informatics
Center for Autism and Related Disorders
Department of Neuropsychology
Kennedy Krieger Institute

Assistant Professor
Department of Mental Health
Johns Hopkins Bloomberg School of Public Health

Chair, National Research Consortium on MH-IDD
Center for START Services
University of New Hampshire

JOHNS HOPKINS
BLOOMBERG SCHOOL of PUBLIC HEALTH

Kennedy Krieger Institute
UNLOCKING POTENTIAL

Outline

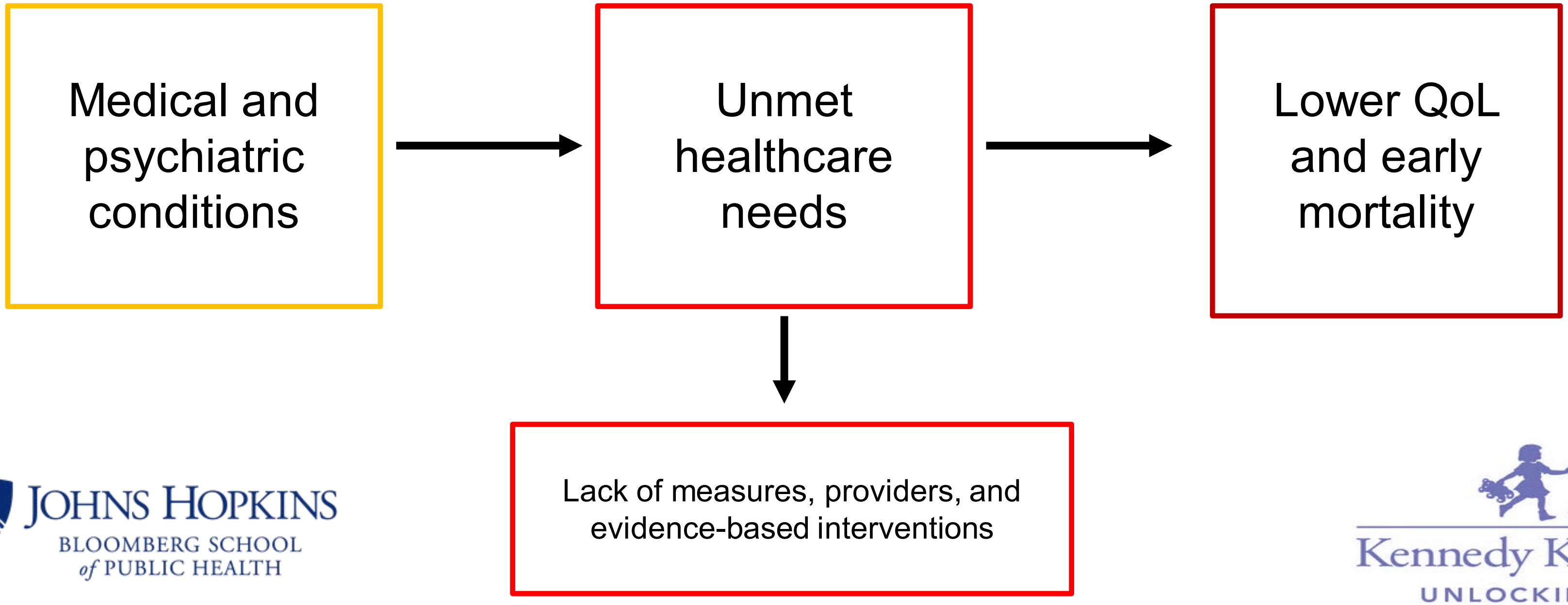
- Discuss the concept of a Learning Healthcare System and its application to Intellectual and Developmental Disabilities (IDD)
- Review the development and implementation of Kennedy Krieger's clinical informatics program
- Identify the promise and pitfalls in IDD clinical informatics

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

Kennedy Krieger Institute
UNLOCKING POTENTIAL

Gaps in IDD

- Persons with IDD are at risk for experiencing a cascade of disparities



Medical and psychiatric conditions

Unmet healthcare needs

Lower QoL and early mortality

Lack of measures, providers, and evidence-based interventions

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

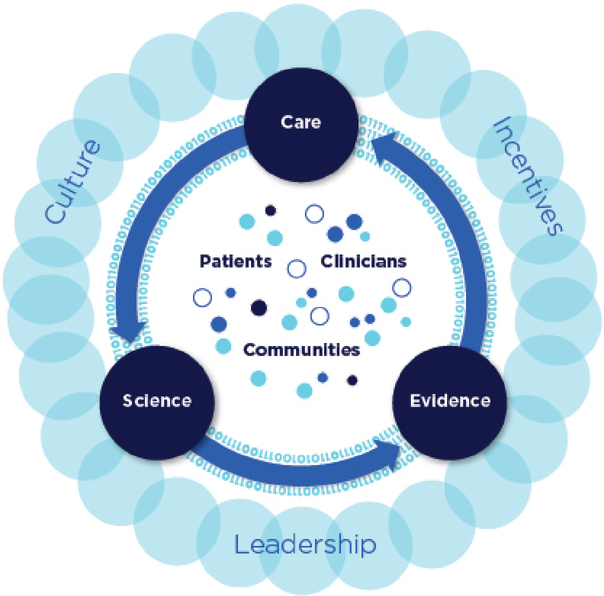
Kennedy Krieger Institute
UNLOCKING POTENTIAL

Krahn, Hammond, & Turner, 2006

Learning Healthcare System (LHS)

- Developed by the IoM, the LHS paradigm seeks to seamlessly integrate research with practice

- The goal is to integrate patient values, clinical acumen, research methodology, and information technologies to “drive the process of discovery as a natural outgrowth of patient care.”



JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

Kennedy Krieger Institute
UNLOCKING POTENTIAL

The Learning Healthcare System, Institute of Medicine, 2007

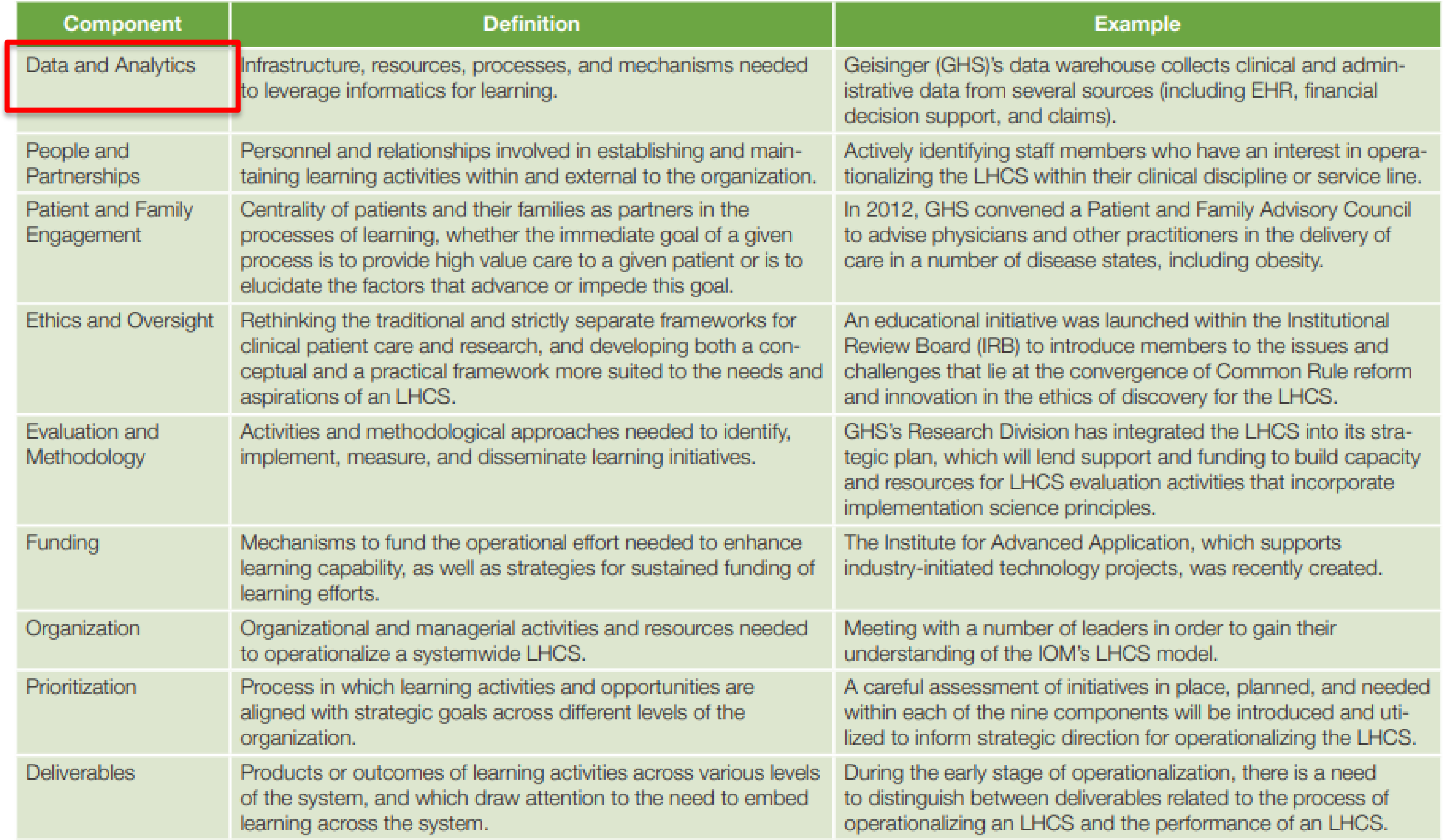
LHS Operates in the Healthcare System

Kennedy Krieger Institute is an internationally recognized institution dedicated to improving the lives of children and young adults with *pediatric developmental disabilities and disorders of the brain.*

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

Kennedy Krieger Institute
UNLOCKING POTENTIAL

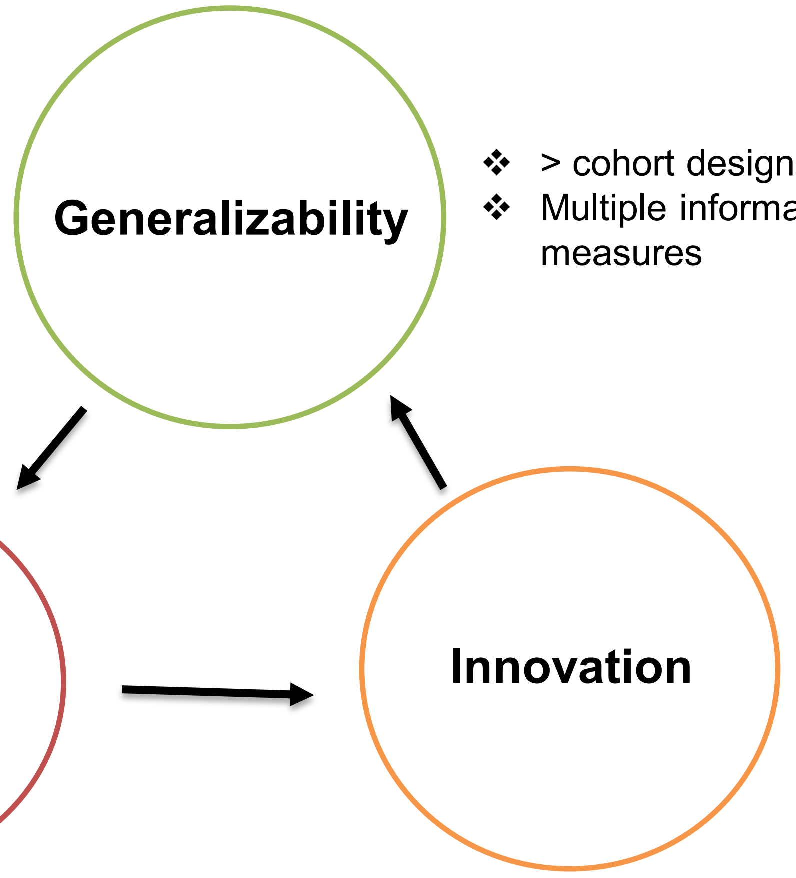
LHS Framework



Component	Definition	Example
Data and Analytics	Infrastructure, resources, processes, and mechanisms needed to leverage informatics for learning.	Geisinger (GHS)'s data warehouse collects clinical and administrative data from several sources (including EHR, financial decision support, and claims).
People and Partnerships	Personnel and relationships involved in establishing and maintaining learning activities within and external to the organization.	Actively identifying staff members who have an interest in operationalizing the LHCS within their clinical discipline or service line.
Patient and Family Engagement	Centrality of patients and their families as partners in the processes of learning, whether the immediate goal of a given process is to provide high value care to a given patient or is to elucidate the factors that advance or impede this goal.	In 2012, GHS convened a Patient and Family Advisory Council to advise physicians and other practitioners in the delivery of care in a number of disease states, including obesity.
Ethics and Oversight	Rethinking the traditional and strictly separate frameworks for clinical patient care and research, and developing both a conceptual and a practical framework more suited to the needs and aspirations of an LHCS.	An educational initiative was launched within the Institutional Review Board (IRB) to introduce members to the issues and challenges that lie at the convergence of Common Rule reform and innovation in the ethics of discovery for the LHCS.
Evaluation and Methodology	Activities and methodological approaches needed to identify, implement, measure, and disseminate learning initiatives.	GHS's Research Division has integrated the LHCS into its strategic plan, which will lend support and funding to build capacity and resources for LHCS evaluation activities that incorporate implementation science principles.
Funding	Mechanisms to fund the operational effort needed to enhance learning capability, as well as strategies for sustained funding of learning efforts.	The Institute for Advanced Application, which supports industry-initiated technology projects, was recently created.
Organization	Organizational and managerial activities and resources needed to operationalize a systemwide LHCS.	Meeting with a number of leaders in order to gain their understanding of the IOM's LHCS model.
Prioritization	Process in which learning activities and opportunities are aligned with strategic goals across different levels of the organization.	A careful assessment of initiatives in place, planned, and needed within each of the nine components will be introduced and utilized to inform strategic direction for operationalizing the LHCS.
Deliverables	Products or outcomes of learning activities across various levels of the system, and which draw attention to the need to embed learning across the system.	During the early stage of operationalization, there is a need to distinguish between deliverables related to the process of operationalizing an LHCS and the performance of an LHCS.

Psek, 2015, eGems

LHS as an opportunity to reduce disparities



- > cohort designs
- Multiple informants, multiple measures

- Reduce stigma, exclusion
- Focus on outcomes that matter

- Reduces inefficiencies (e.g., hospitalizations)
- Evaluates real-world care

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

For an LHS to function, there must be high-quality data.

Kennedy Krieger Institute
UNLOCKING POTENTIAL

Kennedy Krieger Clinical Informatics Timeline

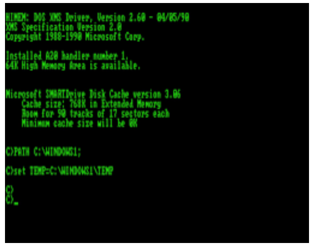
Build & Test

Implementation

Extraction & Recruitment

2012

Multiple, disparate outpatient data collection efforts; most of which was based on custom electronic health record



```
HIMEM: DOS XMS Driver, Version 2.60 - 04/05/90
XMS Specification Version 2.0
Copyright 1988-1990 Microsoft Corp.

Installed A20 handler number 1.
64K High Memory Area is available.


Microsoft SMARTDrive Disk Cache version 3.06
    Cache size: 768K in Extended Memory
    Room for 90 tracks of 17 sectors each
    Minimum cache size will be 0K


C>PATH C:\WINDOWS1;

C>set TEMP=C:\WINDOWS1\TEMP

C>
C>_
```

July, 2018

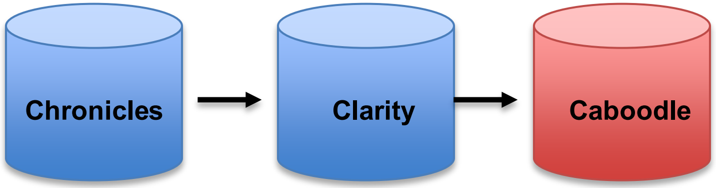
Epic Installation Began

July, 2019

Go Live!

Today

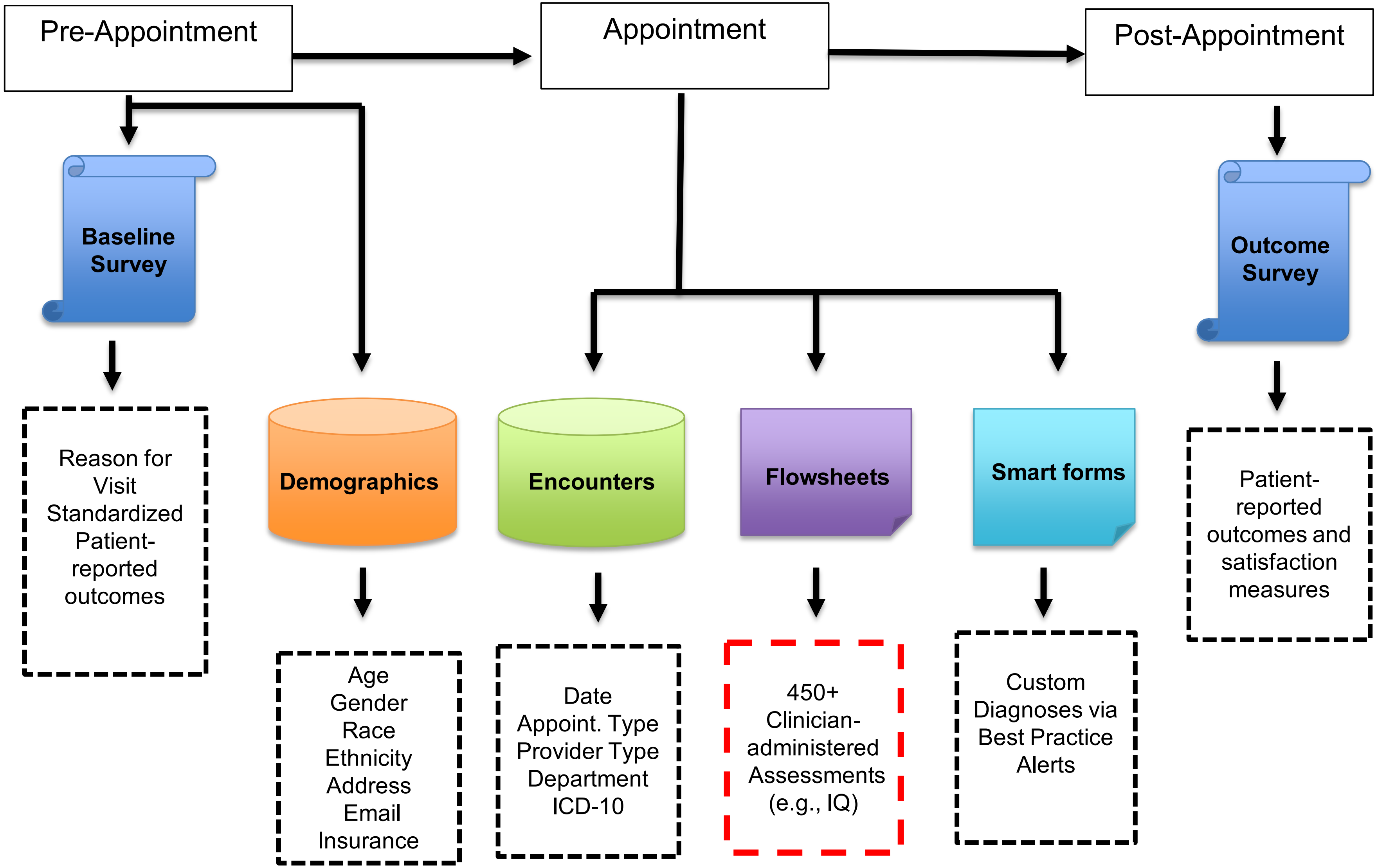
Epic



JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

ger Institute
POTENTIAL

The Quantified Visit



Pre-Appointment

Baseline Survey

Reason for Visit
Standardized Patient-reported outcomes

Demographics

Age
Gender
Race
Ethnicity
Address
Email
Insurance

Appointment

Encounters

Date
Appoint. Type
Provider Type
Department
ICD-10

Flowsheets

450+ Clinician-administered Assessments (e.g., IQ)

Smart forms

Custom Diagnoses via Best Practice Alerts

Post-Appointment

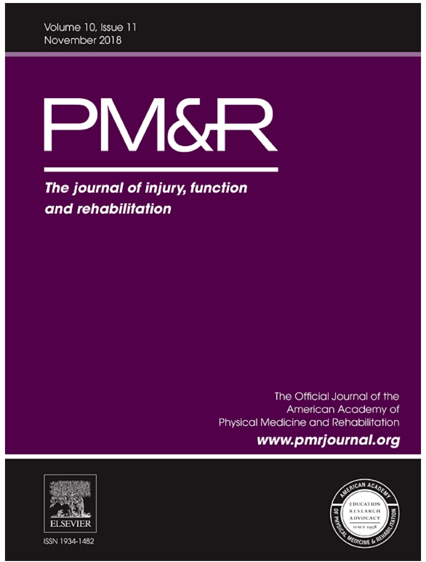
Outcome Survey

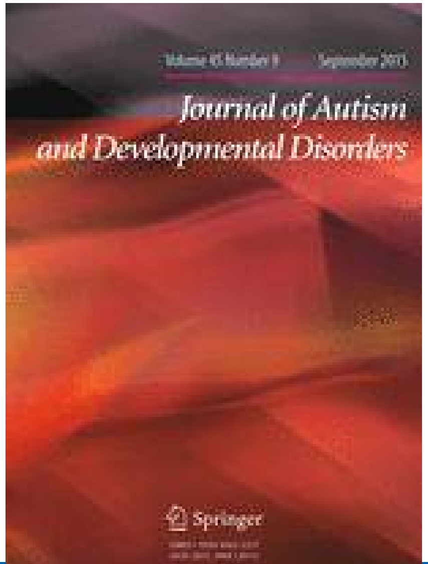
Patient-reported outcomes and satisfaction measures

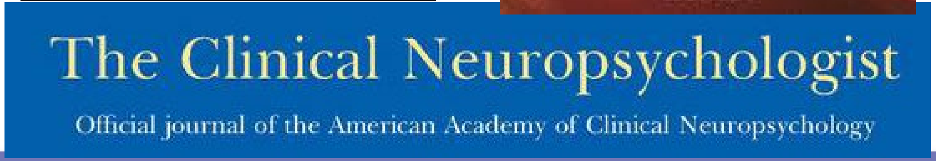
Examples of Kennedy Krieger work


Journal of Developmental & Behavioral Pediatrics
Official Journal of the Society for Developmental and Behavioral Pediatrics


PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS


Volume 10, Issue 11
November 2018
PM&R
The journal of injury, function and rehabilitation
The Official Journal of the American Academy of Physical Medicine and Rehabilitation
www.pmrjournal.org
ELSEVIER
ISSN 1934-1482


Journal of Autism and Developmental Disorders
Springer


The Clinical Neuropsychologist
Official journal of the American Academy of Clinical Neuropsychology

Patrick, K. E., McCurdy, M. D., Chute, D. L., Mahone, E. M., Zabel, T. A., & Jacobson, L. A. (2013). Clinical utility of the Colorado learning difficulties questionnaire. *Pediatrics*, *132*(5), e1257-e1264.

Kalb, L., Freedman, B., Foster, C., Menon, D., Kisfy, L., Landa, R., & Law, P (2012). Determinants of Appointment Attendance at an Outpatient Pediatric Autism Clinic. *Journal of Developmental and Behavioral Pediatrics* 33 (9), 685-697.

Kalb, L., Jacobson, L., Zisman, et al. (2019) Interest in Research Participation among Caregivers Raising a Child with a Neurodevelopmental Disability. *Journal of Autism and Developmental Disorders.*

Coslick, A. M., Chin, K. E., Kalb, L. G., Slomine, B. S., & Suskauer, S. J. (2020). Participation in physical activity at time of presentation to a specialty concussion clinic is associated with shorter time to recovery. *PM&R*, *12*(12), 1195-1204.

Jacobson, L. A., Kalb, L. G., & Mahone, E. M. (2019). When theory met data: factor structure of the BRIEF2 in a clinical sample. *The Clinical Neuropsychologist*, 1-16.

ieger Institute
G POTENTIAL

[redacted]

Strengths

- Relatively low cost. Highly sustainable.
- Access to high-quality, expensive, developmental assessments (see Flowsheet). Epic supports a flowsheet universe for collaboration.
- Overcome biases in billing diagnoses (see smart forms).
- Large, generalizable sample. Real-world outcomes.
- Ability to track changes over time (both patient-reported and standardized assessments).
- Access to multiple informants (caregiver, clinician, teacher, etc.)
- Well-designed to investigate social determinants of health, inequities, and measures.
- Can leverage infrastructure for a research match/repository to facilitate recruitment to traditional efficacy studies.

Moving forward

Challenges	Solutions?
Few informatics programs or groups working under the LHS umbrella in IDD Common data model and harmonization.	PedsNet for IDD
Treatment fidelity for CER Overcoming barriers to LHS implementation	Implementation Science
Long-term, post-intervention follow-up	Integrate consent with practice
Causal Inference	Expand partnerships (biostatistics/epidemiology), use of research match/centralize repository for efficacy studies

Thank You!

Contact: kalb@kennedykrieger.org

JOHNS HOPKINS
BLOOMBERG SCHOOL
of PUBLIC HEALTH

Kennedy Krieger Institute
UNLOCKING POTENTIAL

Topic 2: Issues in Observational and Interventional Designs

Panel Discussion

David Mandell, ScD

Professor and Director, Penn Center for Mental Health

University of Pennsylvania School of Medicine

Luther G Kalb, PhD

Director of Informatics, Center for Autism and Related Disorders, Department of Neuropsychology

Kennedy Krieger Institute

Assistant Professor, Department of Mental Health

Johns Hopkins Bloomberg School of Public Health

Daniele Fallin, PhD

Sylvia and Harold Halpert Professor and Chair, Department of Mental Health, Johns Hopkins Bloomberg School of Public Health

Director, Wendy Klag Center for Autism & Developmental Disabilities

Co-Director, Genetics Core, Claude D. Pepper Older Americans Independence Center

Danny van Leeuwen, MPH, RN, CPHQ

Founder, Health Hats

Board of Governors Member, PCORI

Break

10 minutes

Topic 3: Heterogeneity

Speakers

Sarabeth Broder-Fingert, M.D., M.P.H.
Associate Professor of Pediatrics
Boston University School of Medicine
Boston Medical Center

Tawara D. Goode
Director, Georgetown University Center for Excellence in Developmental Disabilities,
Director, Georgetown University National Center for Cultural Competence
Assistant Professor, Department of Pediatrics
Georgetown University Medical Center

HETEROGENEITY AND AUTISM RESEARCH: CHALLENGE OR OPPORTUNITY?

Sarabeth Broder-Fingert, MD, MPH

Associate Professor of Pediatrics

Boston University School of Medicine

Boston Medical Center

@SBroderFingert

What Heterogeneity?

Clinical presentation of ASD

Families of children with ASD

Systems and Service Structures for ASD

Expert Review | Open Access | Published: 07 January 2019

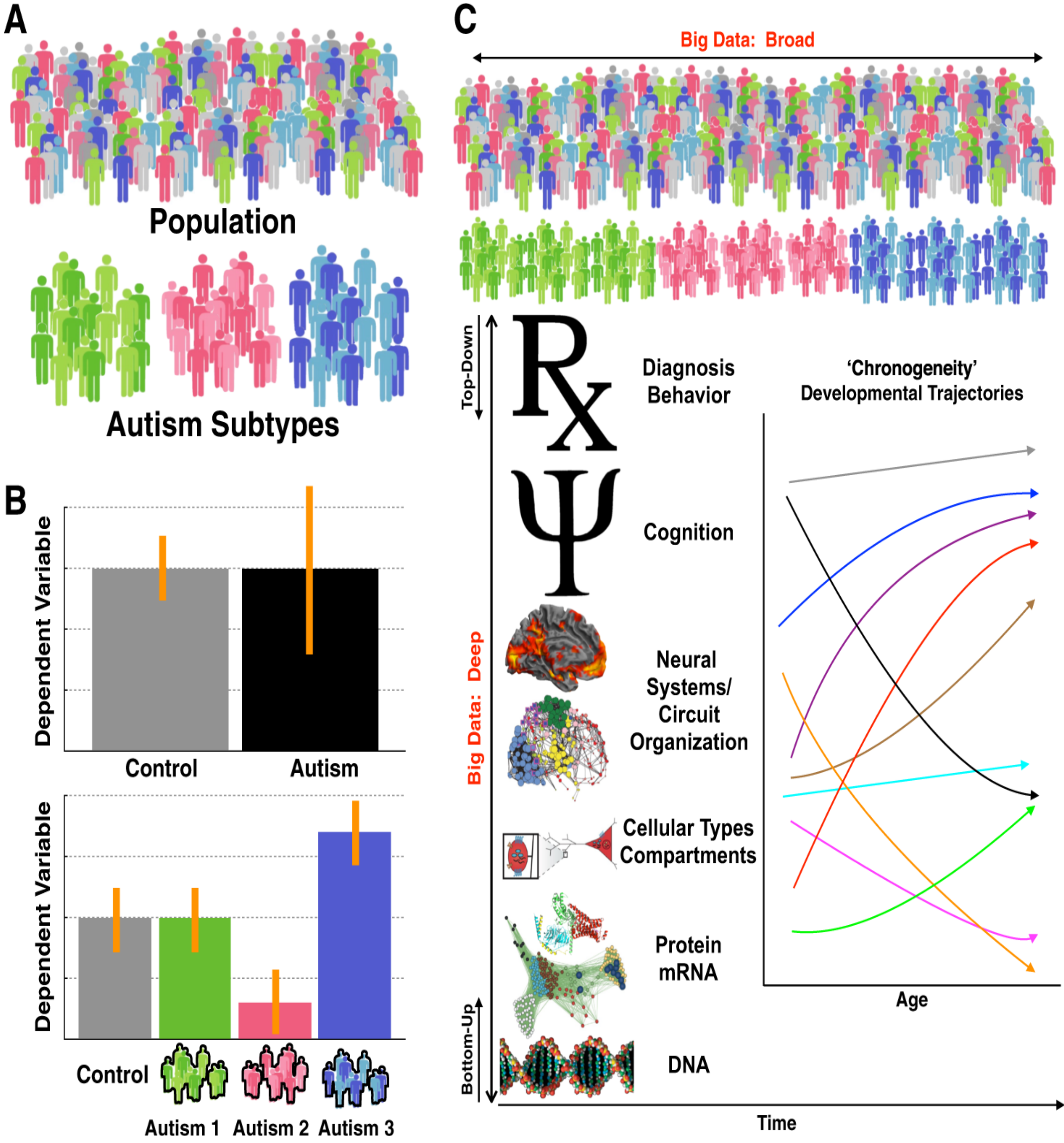
Big data approaches to decomposing heterogeneity across the autism spectrum

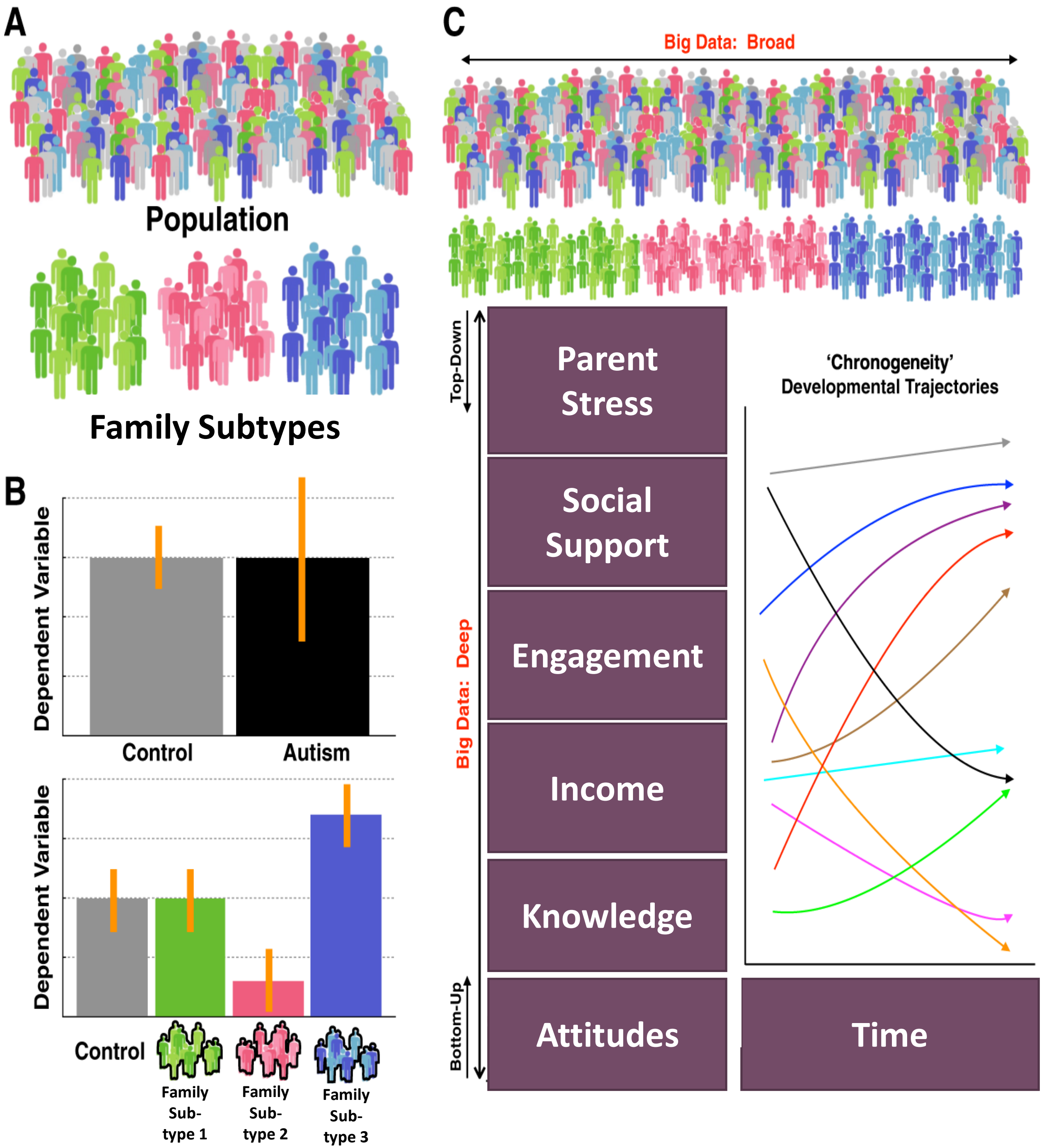
Michael V. Lombardo, Meng-Chuan Lai & Simon Baron-Cohen

Molecular Psychiatry **24**, 1435–1450(2019) | Cite this article

---

CLINICAL PRESENTATION





FAMILY PRESENTATION

"The final model revealed that the individual predictors, initial parental buy-in (8%), ratings of caregiver involvement at exit to the study (5%), parental use of mirrored pacing and environmental arrangement (30%), and treatment (12%) all significantly predicted a combined total of 55% of the variance in joint engagement"

WHY WOULD FAMILY PROFILE IMPACT AUTISM TREATMENT?

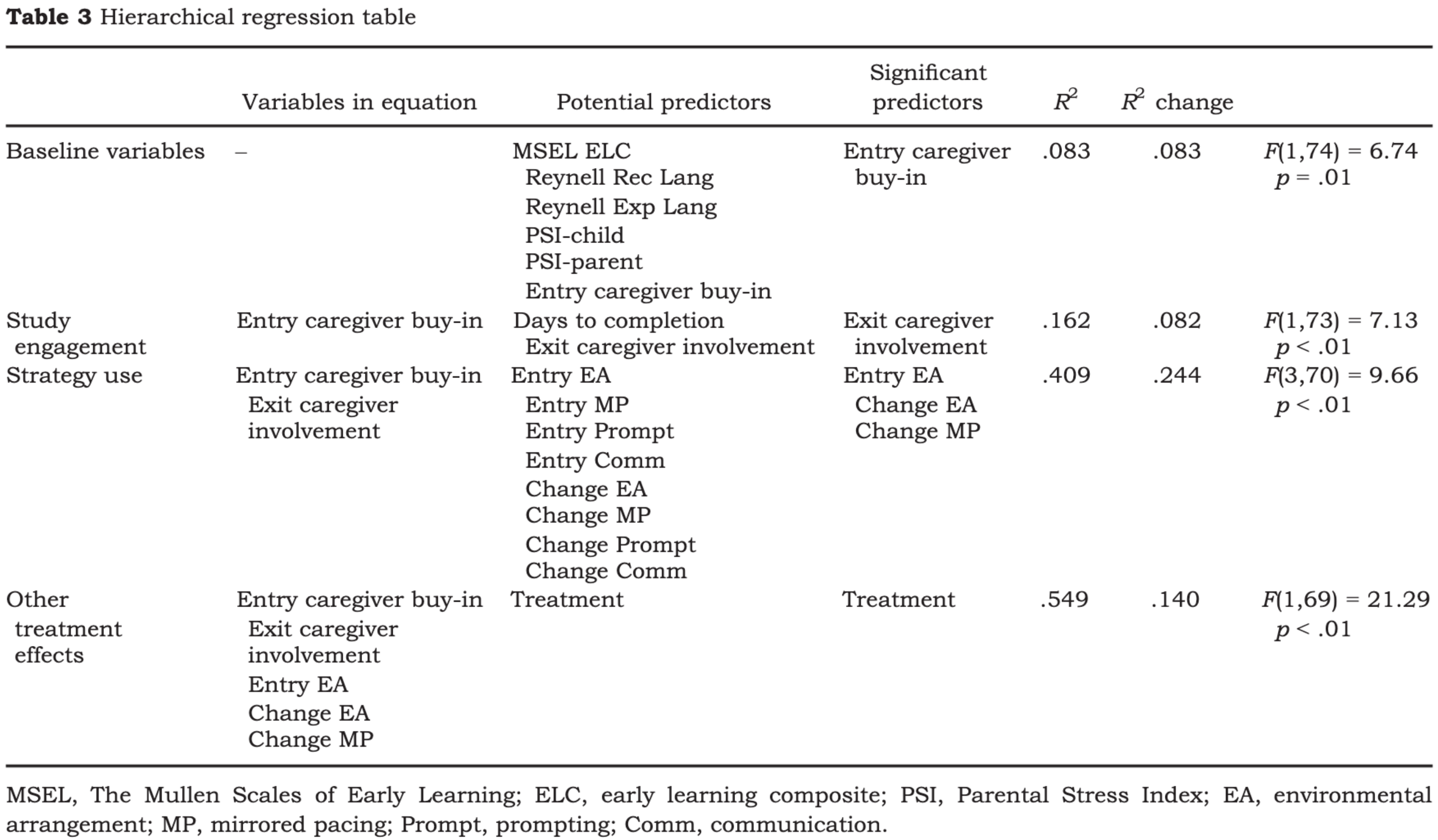


Table 3 Hierarchical regression table

	Variables in equation	Potential predictors	Significant predictors	R^2	R^2 change	
Baseline variables	–	MSEL ELC Reynell Rec Lang Reynell Exp Lang PSI-child PSI-parent Entry caregiver buy-in	Entry caregiver buy-in	.083	.083	$F(1,74) = 6.74$ $p = .01$
Study engagement	Entry caregiver buy-in	Days to completion Exit caregiver involvement	Exit caregiver involvement	.162	.082	$F(1,73) = 7.13$ $p < .01$
Strategy use	Entry caregiver buy-in Exit caregiver involvement	Entry EA Entry MP Entry Prompt Entry Comm Change EA Change MP Change Prompt Change Comm	Entry EA Change EA Change MP	.409	.244	$F(3,70) = 9.66$ $p < .01$
Other treatment effects	Entry caregiver buy-in Exit caregiver involvement Entry EA Change EA Change MP	Treatment	Treatment	.549	.140	$F(1,69) = 21.29$ $p < .01$

MSEL, The Mullen Scales of Early Learning; ELC, early learning composite; PSI, Parental Stress Index; EA, environmental arrangement; MP, mirrored pacing; Prompt, prompting; Comm, communication.

FAMILY FACTORS PREDICT *MORE* OF THE VARIANCE THAN THE TREATMENT

Parental beliefs = 13%

- parental buy-in (8%)
- caregiver reported involvement (5%)

Parental actions (fidelity) = 30%

- mirrored pacing and environmental arrangement (30%)

Treatment = 12%

FAMILY FACTORS

FAMILY FACTORS

HEALTH AFFAIRS BLOG

RELATED TOPICS:
RACISM | HEALTH DISPARITIES | HEALTH OUTCOMES | DISEASES | ACCESS TO CARE

On Racism: A New Standard For Publishing On Racial Health Inequities

Rhea W. Boyd, Edwin G. Lindo, Lachelle D. Weeks, Monica R. McLemore

Critical Race Theory

Family doesn't fully understand materials

Family doesn't implement all components

Low fidelity

- Worse outcomes

Family doesn't fully understand materials

- Materials are in English

Family doesn't implement all components

- English-speaking trainer can't explain

Low fidelity

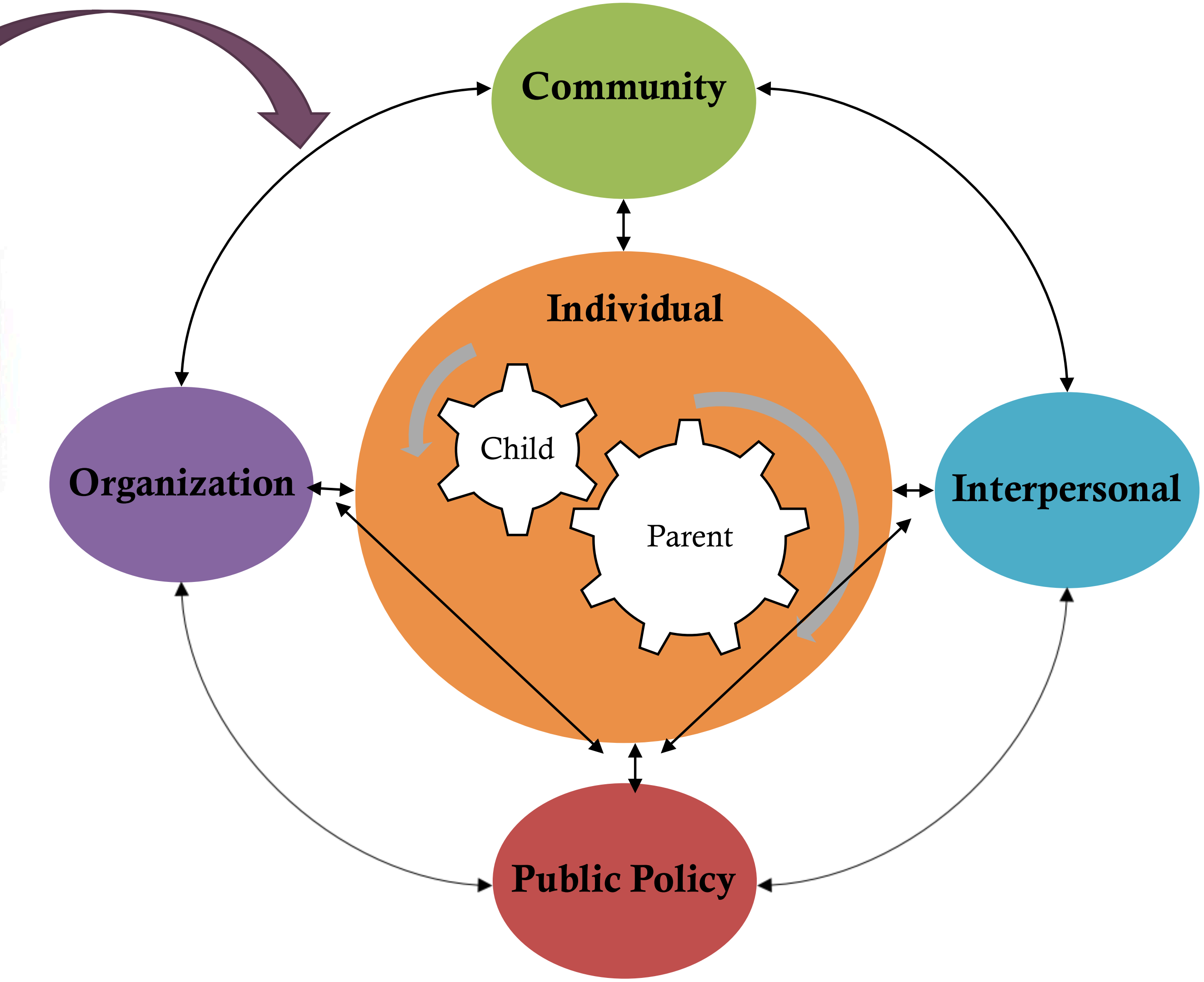
- Worse outcomes

Structural Racism and Autism

Sarabeth Broder-Fingert, MD, MPH,[a] Camila M. Mateo, MD, MPH,[b] Katherine E. Zuckerman, MD, MPH[c]

SYSTEMS AND SERVICE STRUCTURES

Figure 1. Socio-ecological model: framework for prevention, centers for disease control. Available from the Centers for Disease Control and Prevention (CDC). http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html.[4]

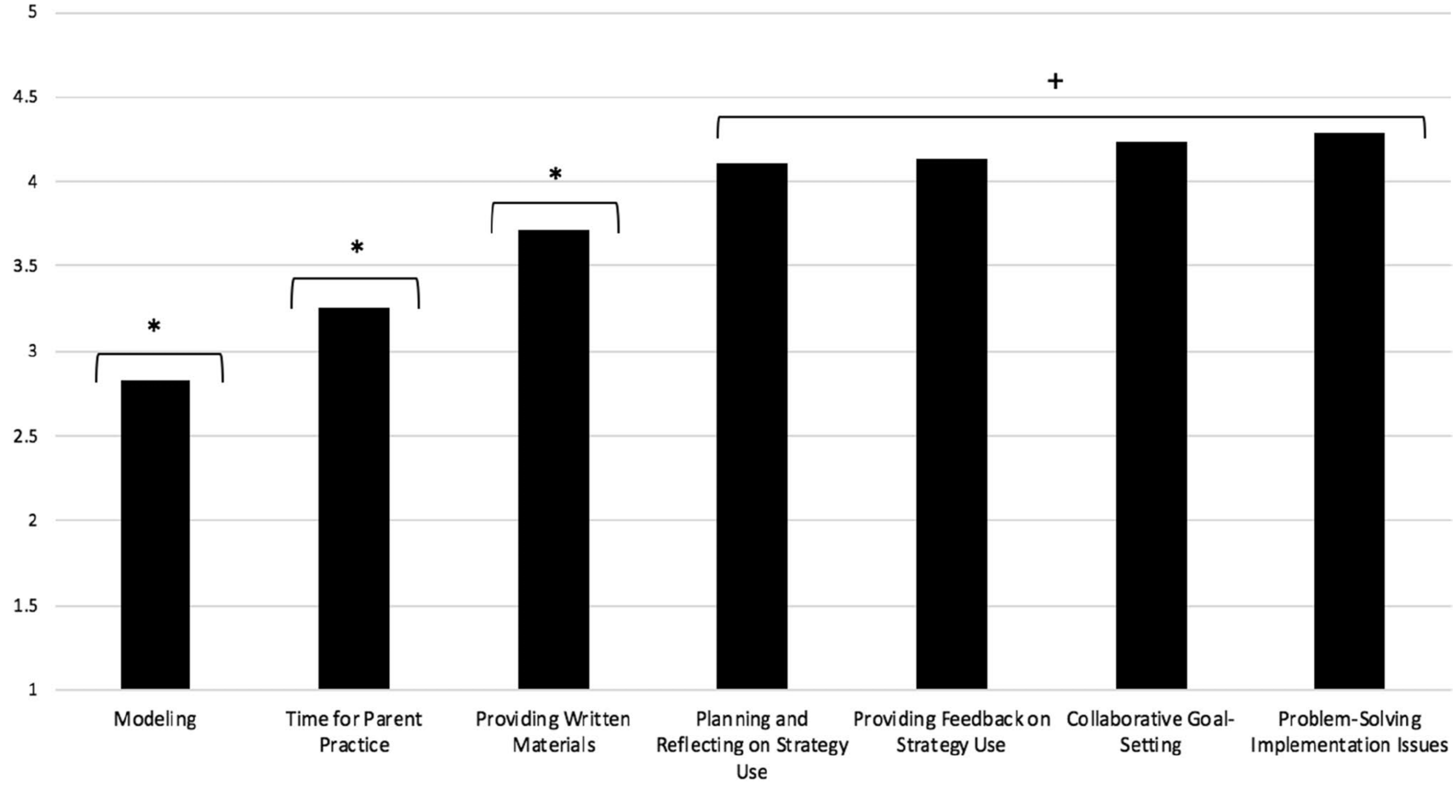


PEDIATRICIANS HAVE DIFFICULTY RECOGNIZING ASD RISK IN SPANISH-SPEAKING FAMILIES

How difficult is it to recognize the signs/symptoms of ASD in each group?	% of Pediatricians saying somewhat/very difficult (*n* = 267)
Non-Latino white	33.2%
Latino/English	34.8%
Latino/Spanish	60.4%*
African American	37.6%*

*P < 0.05 compared to non-Latino white

Zuckerman et al, Pediatrics, 2013




Journal of Autism and Developmental Disorders
https://doi.org/10.1007/s10803-020-04679-x

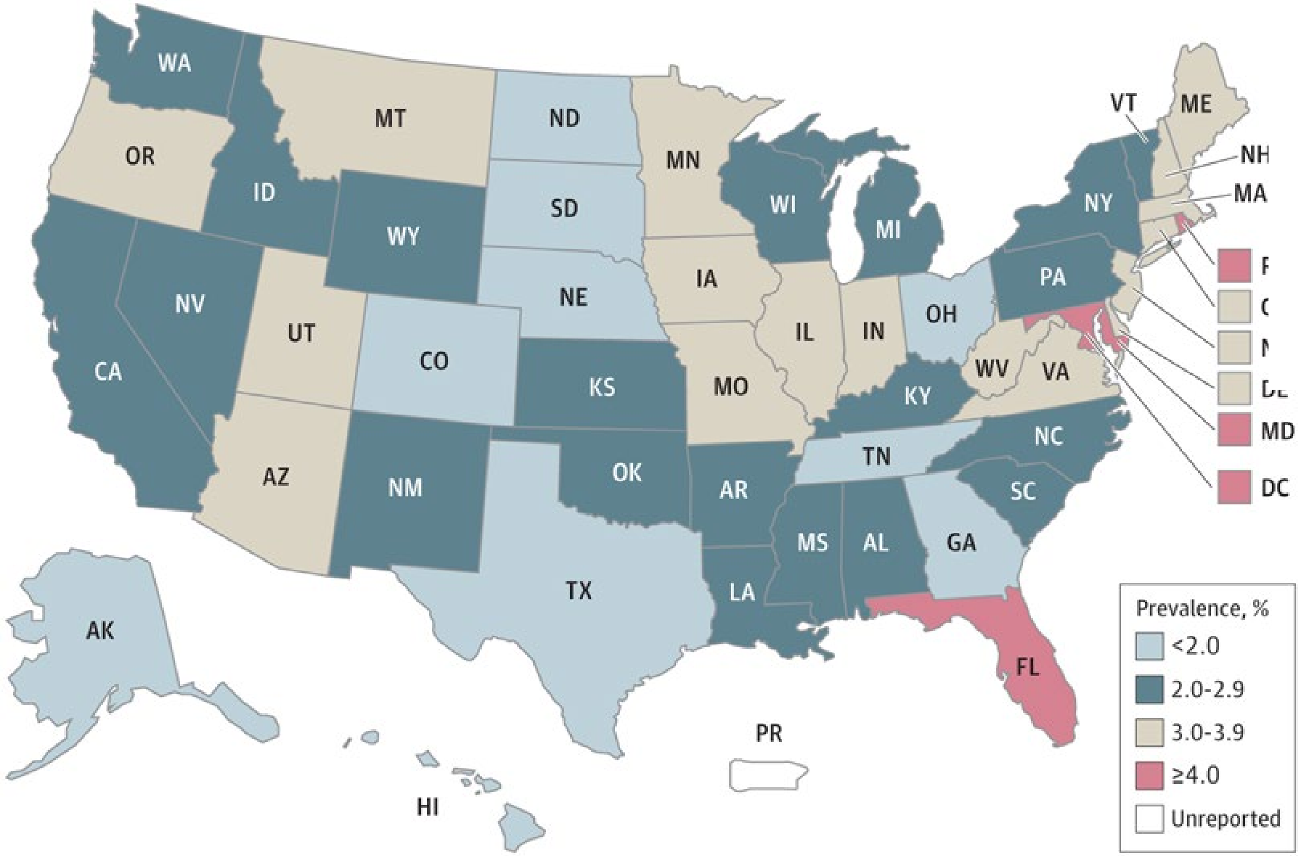
ORIGINAL PAPER

Parent Training for Youth with Autism Served in Community Settings: A Mixed-Methods Investigation Within a Community Mental Health System

Diondra Straiton[1] · Barb Groom[2] · Brooke Ingersoll[1]

HETEROGENEITY AT THE PROVIDER LEVEL

ASD LESS LIKELY TO BE DIAGNOSED BY GEOGRAPHY



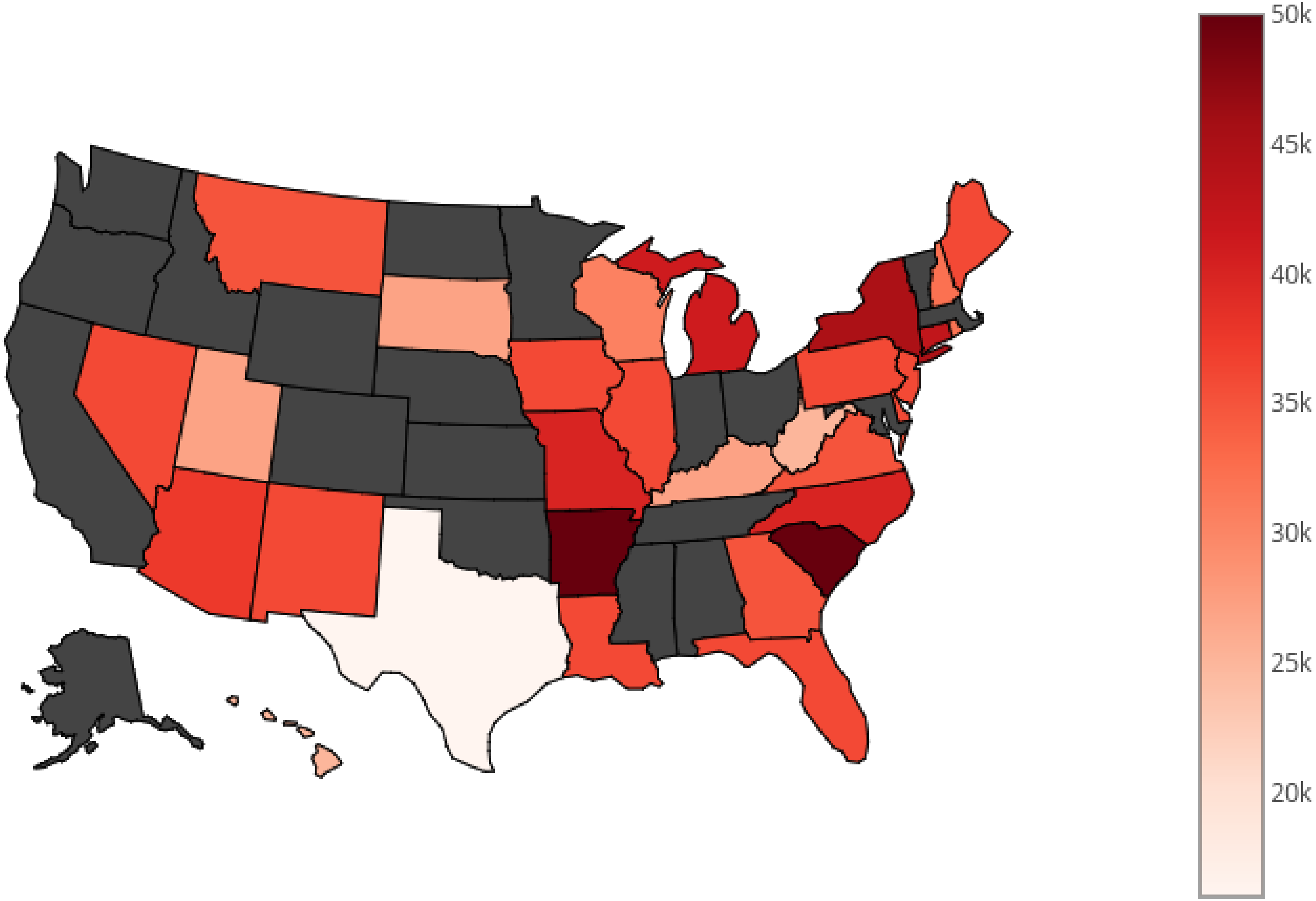
The Value of State Differences in Autism When Compared to a National Prevalence Estimate

Sarabeth Broder-Fingert, MD, MPH,[a] Christopher R. Sheldrick, PhD,[b] Michael Silverstein, MD, MPH[a]

HETEROGENEITY BY STATE

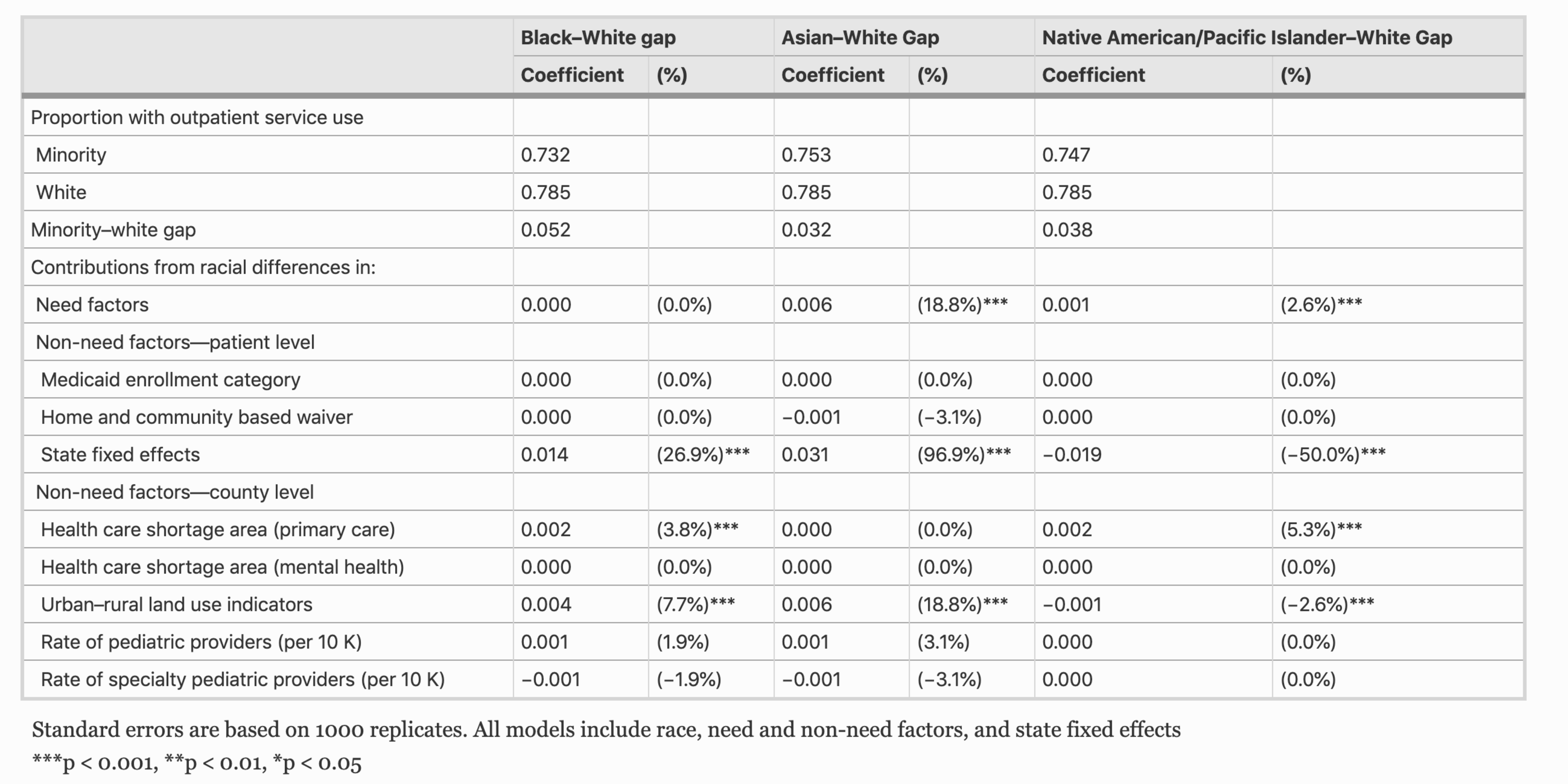
State	Are insurers required to cover autism treatment?	Individual plans	Large employer plans (not including self-insured)	Small employer plans	State employee plans	Treatment cap (sometimes not enforced)	Age cap
Arizona	Yes	No	Yes	No	Yes	0-8 years old: $50,000 9-16 years old: $25,000	16
California	Yes	No	Yes	No	Yes	$36,000	21
Connecticut	Yes	No	Yes	Yes	Yes	0-8 years old: $50,000 9-12 years old: $35,000 13-14 years old: $25,000	15
Massachusetts	Yes	Yes	Yes	Yes	Yes	None	None
Pennsylvania	Yes	Yes	Yes	Yes	Yes	None	None

R01MH121599



Treatment cap (states in gray have no cap, do not cover autism treatment, or cap based on hours/week)

DECOMPOSITION OF SIGNIFICANT DISPARITIES IN OUTPATIENT AUTISM-RELATED SERVICE USE AMONG MEDICAID ENROLLED CHILDREN

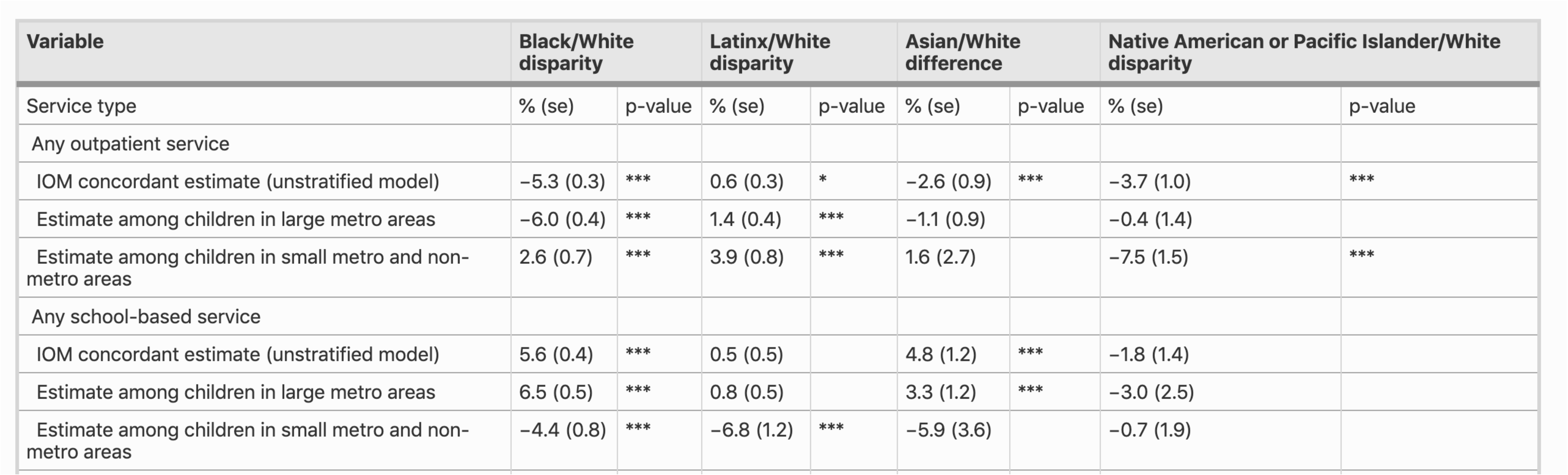


	Black–White gap		Asian–White Gap		Native American/Pacific Islander–White Gap	
	Coefficient	**(%)**	**Coefficient**	**(%)**	**Coefficient**	**(%)**
Proportion with outpatient service use						
Minority	0.732		0.753		0.747	
White	0.785		0.785		0.785	
Minority–white gap	0.052		0.032		0.038	
Contributions from racial differences in:						
Need factors	0.000	(0.0%)	0.006	(18.8%)***	0.001	(2.6%)***
Non-need factors—patient level						
Medicaid enrollment category	0.000	(0.0%)	0.000	(0.0%)	0.000	(0.0%)
Home and community based waiver	0.000	(0.0%)	−0.001	(−3.1%)	0.000	(0.0%)
State fixed effects	0.014	(26.9%)***	0.031	(96.9%)***	−0.019	(−50.0%)***
Non-need factors—county level						
Health care shortage area (primary care)	0.002	(3.8%)***	0.000	(0.0%)	0.002	(5.3%)***
Health care shortage area (mental health)	0.000	(0.0%)	0.000	(0.0%)	0.000	(0.0%)
Urban–rural land use indicators	0.004	(7.7%)***	0.006	(18.8%)***	−0.001	(−2.6%)***
Rate of pediatric providers (per 10 K)	0.001	(1.9%)	0.001	(3.1%)	0.000	(0.0%)
Rate of specialty pediatric providers (per 10 K)	−0.001	(−1.9%)	−0.001	(−3.1%)	0.000	(0.0%)

Standard errors are based on 1000 replicates. All models include race, need and non-need factors, and state fixed effects

***$p < 0.001$, **$p < 0.01$, *$p < 0.05$

DISPARITY IN OUTPATIENT SERVICE USE FOR BLACK CHILDREN WAS DRIVEN LARGELY BY LIVING IN **LARGE METRO COUNTIES**



Variable	Black/White disparity		Latinx/White disparity		Asian/White difference		Native American or Pacific Islander/White disparity	
Service type	% (se)	p-value	% (se)	p-value	% (se)	p-value	% (se)	p-value
Any outpatient service								
IOM concordant estimate (unstratified model)	−5.3 (0.3)	***	0.6 (0.3)	*	−2.6 (0.9)	***	−3.7 (1.0)	***
Estimate among children in large metro areas	−6.0 (0.4)	***	1.4 (0.4)	***	−1.1 (0.9)		−0.4 (1.4)	
Estimate among children in small metro and non-metro areas	2.6 (0.7)	***	3.9 (0.8)	***	1.6 (2.7)		−7.5 (1.5)	***
Any school-based service								
IOM concordant estimate (unstratified model)	5.6 (0.4)	***	0.5 (0.5)		4.8 (1.2)	***	−1.8 (1.4)	
Estimate among children in large metro areas	6.5 (0.5)	***	0.8 (0.5)		3.3 (1.2)	***	−3.0 (2.5)	
Estimate among children in small metro and non-metro areas	−4.4 (0.8)	***	−6.8 (1.2)	***	−5.9 (3.6)		−0.7 (1.9)	

CONCLUSIONS

1. Heterogeneity in clinical presentation, families, systems and service structures
2. Heterogeneity impacts both **family needs** and **clinical outcomes**
3. Heterogeneity creates **opportunities** to better the lives of autistic individuals and their families thru interventions that are directed at **families, treatment providers, service systems and policy**

Recognizing and Responding to Diversity Among Persons with Intellectual and Developmental Disabilities in Research

Tawara D. Goode
Georgetown University National Center for Cultural Competence
University Center for Excellence in Developmental Disabilities
Center for Child and Human Development
Georgetown University Medical Center

March 15, 2021

GEORGETOWN UNIVERSITY
National Center for
Cultural Competence

GEORGETOWN UNIVERSITY
Center for Child and
Human Development

GEORGETOWN UNIVERSITY
Georgetown University Medical Center

Who are persons with intellectual and developmental disabilities?

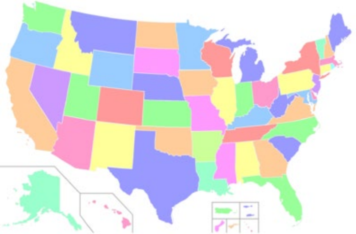
Prevalence of Intellectual or Developmental Disabilities

Currently, there is no systemic national research effort addressing the prevalence and health status of adults with IDD. While the ACS, CPS, and SIPP collect data, the identification questions are too broad to be useful in identifying people with IDD based on statutory definitions used in federal government. [1]

There were an estimated 7.37 million adults and children with IDD in the U.S. in 2016 (using IDD prevalence rates for 1994-95 NHIS for adults and children, 2016 U.S. Census, and data on people in congregate settings in 2016).[2]

It was estimated that about 17% of children aged 3- 17 years have one or more developmental disabilities, representing an increase between 2009-2017.[3]

While we do not know exact numbers, we do know persons with IDD are members of this nation's racially, ethnically, and linguistically diverse groups.



ACS 2019 United States Demographic Estimates

One Race or Latino or Hispanic and Race

Total Population = 328,239,523

RACE	NUMBER	Percent of POPULATION
One Race	316,930,628	96.6%
White	236,475,401	72.0%
Black or African American	41,989,671	12.8%
American Indian or Alaska Native	2,847,336	0.9%
Asian	18,636,984	5.7%
Native Hawaiian & Other Pacific Islander	628,683	0.2%
Some Other Race	16,352,553	5.0%
Two or More Races	11,308,895	3.4%
HISPANIC OR LATINO AND RACE		
Hispanic or Latino of any Race	60,481,746	18.4%

Data Source: Source: U.S. Census Bureau, 2019 American Community Survey (ACS), Demographic & Housing Estimates, Table DP05, 1-Year Estimates.

Languages Spoken at Home in the U.S. in 2019

Estimated Total Population 5 years and over ***304,930,125***

Speak only English	**238,982,352**	**78.4%**
Speak a language other than English	**65,947,773**	**21.6%**
Speak Spanish	**40,709,597**	**13.4%**
Speak Indo European languages	**11,136,844**	**3.7%**
[French (Patois, Cajun), French Creole, Italian, Portuguese, Portuguese Creole, German, Yiddish, Other West Germanic languages, Scandinavian languages, Greek, Russian, Polish, Serbo-Croatian, Other Slavic languages, Armenian, Persian, Gujarathi, Hindi, Urdu, Other Indic languages]		
Speak Asian and Pacific Island languages	**10,727,303**	**3.5%**
[Chinese, Japanese, Korean, Mon-Khmer, Cambodian, Miao, Hmong, Thai, Laotian, Vietnamese, Tagalog, other Pacific Island languages]		
Other Languages	**3,374,024**	**1.1%**
[Navajo, Other Native American languages, Hungarian, Arabic, Hebrew, African languages, other unspecified languages]		

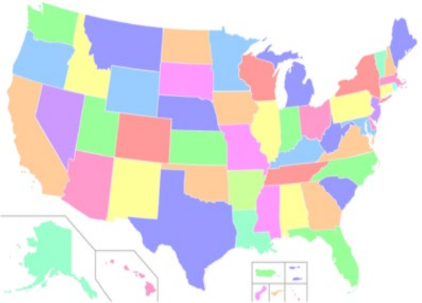
Data Source: U.S. Census Bureau, American Fact Finder, 2019 American Community Survey- 5-Year Estimates, Table DP02

Slide Source:© 2021 - Georgetown University National Center for Cultural Competence

Limited English Speaking Households

Limited English Speaking Households formerly (linguistic isolation) refers to households in which no member 14 years old and over: (1) speaks only English or (2) speaks a non-English language and speaks English “very well.”

Limited English Speaking Households in the Unites States in 2019



All households	4.3%
Households speaking--	
▪ Spanish	20.5%
▪ Other Indo-European languages	14.7%
▪ Asian and Pacific Island languages	23.5%
▪ Other languages	15.0%

Data Source: U.S. Census Bureau, American FactFinder,
2019 American Community Survey- 1 Year Estimates, Table S1602

ACS 2019 U.S. Disability Characteristics

Disability defined as:

- Hearing difficulty
- Vision difficulty
- Cognitive difficulty
- Ambulatory difficulty
- Self-care difficulty
- Living Independent difficulty

Varies by Age Grouping

< 5 years = 0.7%
5-17 years = 5.6%
18-34 years = 6.7%
35-64 years = 12.4%
65-74 years = 24.1%
> 75 years = 47.1%

Total U.S. Population = 323,120,678

Estimated Non-institutionalized Population with a Disability = 41,089,958 (12.7%)

[Margin of error = +/- 0.1]

RACE	NUMBER	Percent of POPULATION
White	30,878,182	13.2%
Black or African American	5,743,213	14.1%
American Indian or Alaska Native	477,954	17.2%
Asian	1,342,054	7.2%
Native Hawaiian & Other Pacific Islander	64,782	10.6%
Some Other Race	1,357,581	8.4%
Two or More Races	1,226,192	11.%
HISPANIC OR LATINO AND RACE		
Hispanic or Latino of any Race	5,405,562	9.1%

Data Source: U.S. Census Bureau, 2019 American Community Survey (ACS), Disability Characteristics, Table S1810

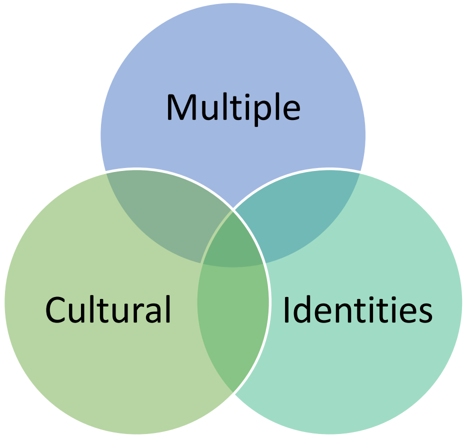
Slide Source:© 2021 - Georgetown University National Center for Cultural Competence

Cultural Diversity

The term *cultural diversity* is used to describe differences in ethnic or racial classification & self-identification, tribal or clan affiliation, nationality, language, age, gender, sexual orientation, gender identity or expression, socioeconomic status, education, religion, spirituality, physical and intellectual abilities, personal appearance, and other factors that distinguish one group or individual from another.

Goode & Jackson, 2009

MULTIPLE CULTURAL IDENTITIES



The extant literature indicates that we as human beings have multiple cultural identities that can be grouped as follows.

- Categorization – people identify with one of their cultural groups over others
- Compartmentalization – individuals maintain multiple, separate identities within themselves
- Integration – people link their multiple cultural identities

Sources:

Seth J.J. Schwartz, Koen Luyckx , and Vivian L.K. Vignoles (Eds.) Handbook of Identity Theory and Research. Springer. 2001.

Verónica Benet-Martínez and Ying-yi Hong (Eds.) The Oxford Handbook of Multicultural Identity. Oxford University Press. 2014.

Chao, G.T., & Moon, H. The Cultural Mosaic: A Metatheory for Understanding the Complexity of Culture. Journal of Applied Psychology 2005, Vol. 90, No. 6, 1128–1140

Yampolsky MA, Amiot CE, & de la Sablonnière, R. (2013). Multicultural identity integration and well-being: a qualitative exploration of variations in narrative coherence and multicultural identification. Front. Psychol. 4:126.doi: 10.3389/fpsyg. 2013.00126

MULTIPLE CULTURAL IDENTITIES THROUGH THE LENS OF ANDY ARIAS

"I come to the table with my LGBTQ-ness, my Hispanic-ness, and my disability. Neither overshadows the other, neither is more important than the other. They are all part of who I am as a person."

Intersectionality

- Kimberlé Crenshaw, a lawyer and civil rights advocate, introduced us to the term ***intersectionality*** in 1991.
- She wrote about how a person who because of their membership in multiple social groups may experience discrimination, oppression, and marginalization. Her work focused on Black women.
- Since 1991, the term intersectionality is used in multiple ways by many in health, mental health, and human services.
- Sometimes those who use the term intersectionality confuse it with multiple cultural identities and omit the important defining factors of discrimination, marginalization, and oppression.

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. Stanford Law Review, Vol. 43, No. 6 (Jul., 1991), pp. 1241-1299.

INTERSECTIONALITY THROUGH THE LENS OF ANDY ARIAS

“From childhood through adult life, I experience stereotyping, marginalization, and discrimination because of my LGBTQ-ness, my Hispanic-ness, and my disability.”

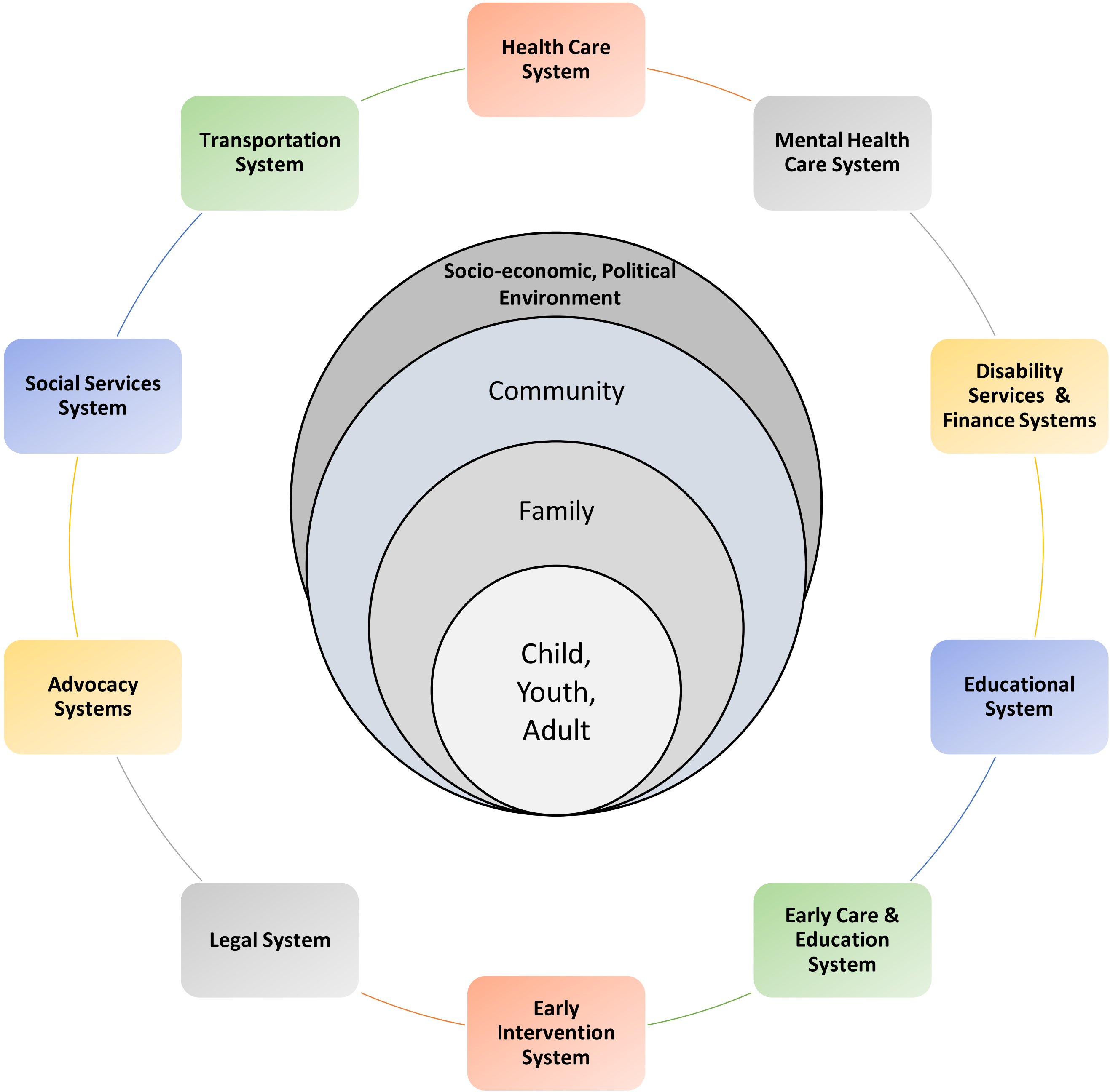
Recognizing and responding to the diversity among persons with IDD will require research methodologies that…

- Avoid the tendency to group all persons with IDD as if they are members of a homogenous group (with the few exceptions of disability categorization, gender, and age).
- Employ approaches that result in a more nuanced portrait of who a person with a IDD is, including the use of mixed methods.
- Describe research participants in a way that delineates the within-group diversity among those with neurodiversity.

  [e.g., race, ethnicity, culture, gender identity and expression, LGBTQI; languages spoken - ASL, languages other than English, level of proficiency in English, other forms of communication; SES; and geographic locale/place].
- Ensure data are collected, analyzed, and reported commensurate with social identities and memberships in addition to neurodevelopmental disability.

Convergence of Cultural Contexts:

A Focus on Neurodevelopmental Disabilities[4]



Health Care System

Mental Health Care System

Disability Services & Finance Systems

Educational System

Early Care & Education System

Early Intervention System

Legal System

Advocacy Systems

Social Services System

Transportation System

Socio-economic, Political Environment

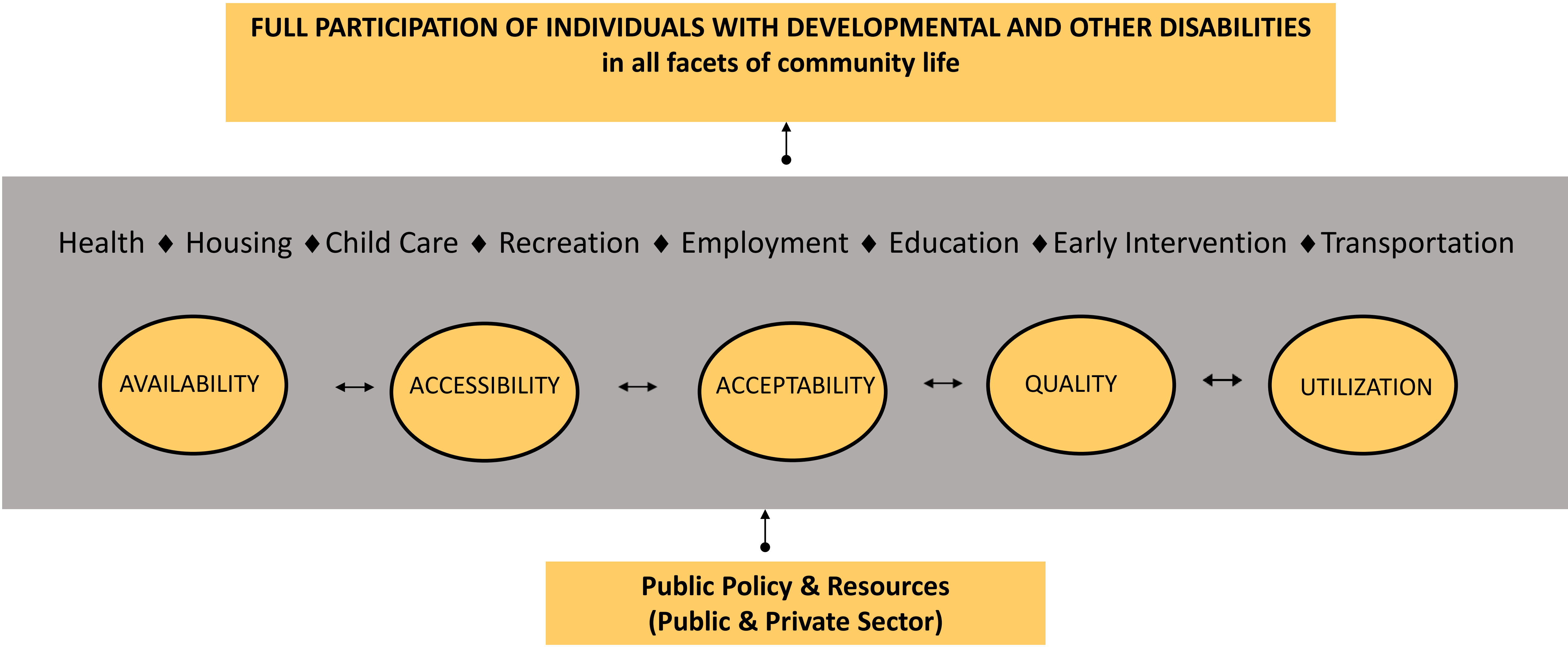
Community

Family

Child, Youth, Adult

Slide Source:© T.D. Goode 2021 - Georgetown University National Center for Cultural Competence

Disparities: A Disability Framework[5]



FULL PARTICIPATION OF INDIVIDUALS WITH DEVELOPMENTAL AND OTHER DISABILITIES in all facets of community life

Health ♦ Housing ♦ Child Care ♦ Recreation ♦ Employment ♦ Education ♦ Early Intervention ♦ Transportation

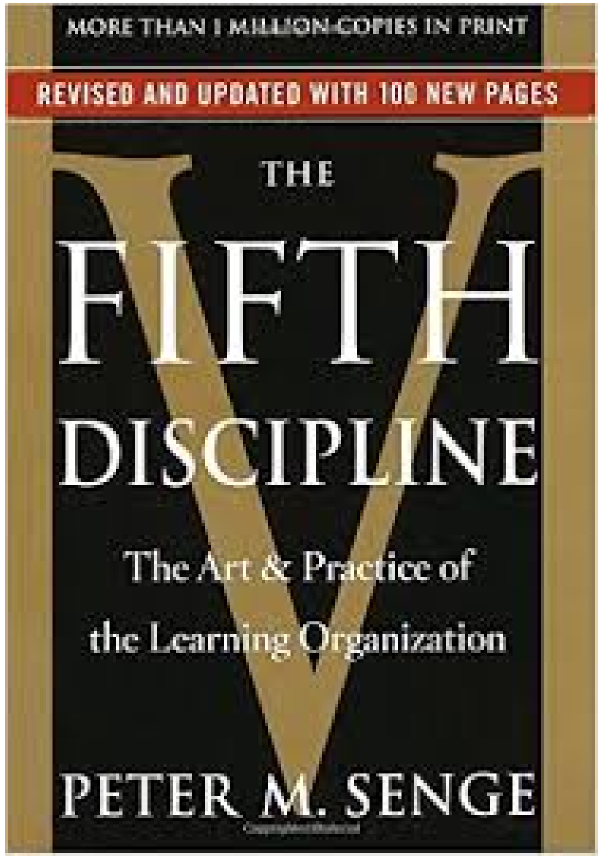
AVAILABILITY ↔ ACCESSIBILITY ↔ ACCEPTABILITY ↔ QUALITY ↔ UTILIZATION

Public Policy & Resources
(Public & Private Sector)

Slide Source:© TD Goode 2021 Georgetown University National Center for Cultural Competence

Some Things Researchers Can Do to Recognize and Respond to Diversity Among Persons with IDD

- Recognize the historical experiences of persons with IDD (across all racial, ethnic, cultural groups) in research
- Be cognizant of the power differentials between universities and research institutions and vulnerable and marginalized communities
- Have capacity to address the power dynamics between researchers and persons with disabilities across cultural groups
- Have the insight and demonstrate the courage to admit and examine one's own biases
- Revisit and revise the terminology and tenor used to describe persons with IDD
- Use methodological approaches that recognize, respect, and address the multiple cultural identities of persons with IDD
- Consider how experiences of persons with IDD vary based on socio-cultural context.
- Use measures and instruments that are appropriate for the diverse racial, ethnic, and cultural groups with IDD, their families, and the communities in which they live
- Employ methodological designs that fosters meaningful partnerships with persons with IDD across cultural groups
- Embed cultural and linguistic competence in methodology
- Increase capacity to include persons with IDD who speak languages other than English and their families in studies



The changes required will be not only in our organizations but in ourselves as well.

... Only by changing how we think can we change deeply embedded policies and practices.

... Only by changing how we interact can shared vision, shared understandings, and new capacities for coordinated action be established."

Senge, Peter. (1990). *The Fifth discipline*, p. xiv

References

[1] Havercamp, S., Krahn, G., Larson, S., Weeks, J.D., & National Health Surveillance for Intellectual and Developmental Disability Work Group (20190. Working through the IDD data conundrum: Identifying people with ID and DD in National Population Surveys. Washington, DC: Administration on Intellectual and Developmental Disabilities.

[2] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016. Research and Training Centers on Community Living, University of Minnesota.

[3] Benjamin Zablotsky, Lindsey I. Black, Matthew J. Maenner, Laura A. Schieve, Melissa L. Danielson, Rebecca H. Bitsko, Stephen J. Blumberg, Michael D. Kogan and Coleen A. Boyle. Prevalence and Trends of Developmental Disabilities among Children in the United States: 2009–2017. Pediatrics October 2019, 144 (4) e20190811; DOI: https://doi.org/10.1542/peds.2019-0811

[4] Goode, T., Jones, W., & Christopher, J. Brown, I., Responding to Cultural and Linguistic Differences among People with Intellectual Disability (2017). In Percy, M., Wehmeyer, M. L., Shogren, K. A., & Fung, A. (Eds.) *A comprehensive guide to intellectual and developmental disabilities* (2nd ed.). Baltimore, MD: Brookes Publishing, pp. 389-400.

[5] Goode, T.D. A Disabilities Disparities Framework. Georgetown University National Center for Cultural Competence . Retrieved from https://nccc.georgetown.edu/resources/disparities-in-idd.php#framework

CONTACT US

Georgetown University National Center for Cultural Competence

http://nccc.georgetown.edu
cultural@georgetown.edu

Topic 3: Heterogeneity

Panel Discussion

Sarabeth Broder-Fingert, M.D., M.P.H.

Associate Professor

Boston University School of Medicine

Tawara D. Goode

Director, Georgetown University Center for Excellence in Developmental Disabilities,

Director, Georgetown University National Center for Cultural Competence

Assistant Professor, Department of Pediatrics

Georgetown University Medical Center

Elizabeth Stuart, PhD

Associate Dean for Education, Professor; Department of Mental Health, Department of Biostatistics, Department of Health Policy and Management

Johns Hopkins Bloomberg School of Public Health

Bradley L Schlaggar, MD, PhD

President & CEO, Zanvyl Krieger Endowed Chair

Kennedy Krieger Institute

Melissa A. Parisi, M.D., Ph.D.

Chief, Intellectual & Developmental Disabilities Branch,DS-Connect® Registry Coordinator

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institutes of Health (NIH)

Closing Remarks

Steven Goodman, MD, MHS, PhD

Associate Dean for Clinical and Translational Research
Professor of Epidemiology & Population Health, and Medicine
Stanford University School of Medicine
Chair, PCORI Methodology Committee