The John J. Conger Lecture
Child Health Services in a Post Affordable Care Act World:
*What Do We Need to Know?*

Dr. Lisa Simpson
President and CEO
March 8, 2013
Lisa Simpson
I have documented that I have no relevant financial relationships with any commercial interests to disclose or Conflicts of Interest (COIs) to resolve.
Outline

- Overview of AcademyHealth
- What do we need to know?
- How will we find out?
- How will we apply what we learn?
- Concluding thoughts
AcademyHealth is a leading national organization serving the fields of health services and policy research and the **professionals who produce and use** this important work.

Together with **our members**, we offer programs and services that support the development and use of rigorous, relevant and timely evidence to:

1. Increase the quality, accessibility and value of health care,
2. Reduce disparities, and
3. Improve health.

A trusted broker of information, AcademyHealth brings stakeholders together to address the current and future needs of an evolving health system, inform health policy, and translate evidence into action.
Leveraging >4,500 Diverse, Expert Members & Organizations

→ Behavioral Health Services Research
→ Child Health Services Research
→ Disability Research
→ Disparities
→ Gender and Health
→ Health Economics
→ Health Information Technology

Child Health IG Meeting
Nemours Award
Student Scholarship
Partnership with Academic Pediatrics

→ Interdisciplinary Research Group on Nursing Issues
→ Long-Term Care
→ Public Health Systems Research
→ Quality & Value
→ Translation & Communications
→ State Health Research and Policy
AcademyHealth Approach

Core Programs
- Generate new knowledge
- Translate evidence into action

Strategic Priorities
- Delivery System Transformation
- Public and Population Health
- Value and Health Care Costs
Conferences

- **Health Policy Orientation**
  - October in Washington, DC
  - Limited to 50 participants

- **National Health Policy Conference (NHPC)**
  - February 4 – 5, 2013 in Washington, DC
  - Nearly 700 attendees

- **Annual Research Meeting (ARM)**
  - June 23-25, 2013 in Baltimore, MD
  - 2,000+ attendees anticipated
New Initiatives

- Partnership with JAMA & HSR
- Annual ARM adjunct meeting on Delivery Systems Transformation
- Translation & Dissemination Institute
- Health Data Consortium
- iHealth Conference
- Expanded focus on population health
New Initiatives

→ Expanded professional development opportunities
  – Senior Scholars program
  – Presidential Scholarships
    • For New Health Services Researchers
    • For Institute on Advocacy & Public Policy
  – Fellowships
    • Public and population health
    • Delivery system science
  – Mentor Matching
Outline

- Overview of AcademyHealth
- What do we need to know?
The Patient Protection and Affordable Care Act and the Future of Child Health Policy

Sara Rosenbaum, JD

“It would be naïve not to acknowledge the implementation challenges that lie ahead, conceptually, operationally, and politically…”
Voltage Drops in Child Health

- Access to Insurance Coverage
  - Enrollment & retention in available insurance plans
- Access to sufficient covered services & providers
- Access to a consistent source of primary care
- Access to referral & wraparound services
- Delivery of high quality care

Modified from Chung & Schuster, Health Affairs, 2004
% of Latino children uninsured dropped from 15% to 10%, still more likely to be uninsured, but gap narrowed

USC changed little, except for low income Latinos

Overall, 52% of children had an annual visit in 2009 compared to 46% in 2002; only black children saw no improvement

Average child health expenditures increase from $1,294 to $1,914 (a 48% increase)
  – Nearly doubled for white children with private insurance

_Berdahl et al, Academic Pediatrics, Forthcoming, 2013_
“Stormy Weather”
The Chain of Effect in Improving Health Care Quality

Environmental context (e.g., policy)

Macro-organization (e.g., health system)

Micro-system of care delivery (e.g., primary care practice)

Child, Family and the Community

Impact of ACOs and provider consolidation on quality of care for children, especially vulnerable children

Trends in coverage and access for low income children in states with and without Medicaid expansions

Comparative effectiveness of different types of approaches for delivering clinical preventive services

Changes in child and family health and wellbeing and distribution of those changes by race/ethnicity & other social determinants

Trends in coverage and access for low income children in states with and without Medicaid expansions

Comparative effectiveness of different types of approaches for delivering clinical preventive services
Let’s Not Forget!

Children’s Health, the Nation’s Wealth, Institute of Medicine, 2004
Key Findings:

- Significant increase in obesity but not overweight
- Growing variation in prevalence across states
- Significant disparities within and across states
- Independent effects of health behavior and health care quality
- Neighborhood access to parks
- State matters
- School outcomes
We Need an “And” Approach

Targeted Research on Disparity Reduction

AND

Disparity/ Equity Dimension in All Designs
Walking the walk

“We need to “move beyond the general recognition that unacceptable disparities exist to the creation of structures and mechanisms to maximize the chance that equity issues will be addressed meaningfully in quality initiatives.”

Marshall Chin and Don Goldman

Source: Chin and Goldman. JAMA, January 26, 2011—Vol 305, No. 4
Outline

» Overview of AcademyHealth
» What do we need to know?
» How will we find out?
Health Services Research

- Health services research is the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately our health and well-being.

- Its research domains are individuals, families, organizations, institutions, communities, and populations."
Health Services Research

→ What works?
→ For whom?
→ Under what circumstances?
→ At what cost?
Provisions in ACA for HSR

→ Investment in HSR to improve healthcare decision making and the healthcare system
  – PCORI (Sec. 6301, corrections Sec. 10602)
  – Delivery system research (Sec. 3501)
  – Research on optimizing the Delivery of Public Health Services (Sec. 4301)
  – Understanding Health Disparities: Data Collection and Analysis (Sec. 4302)
  – National Healthcare Workforce Commission and Assessment (Sec. 5101 and Sec. 5103)
  – Center for Medicare and Medicaid Innovation
The Need for Study on T3- T4

Khoury et al. “no more than 3% of research focuses on T2 and beyond”

Patient Centered Outcomes Research

- Builds on $1.1 billion investment in ARRA
- Funded by
  - FY 2010 - $10 million
  - FY 2011 - $50 million
  - FY 2012 - $150 million
  - FY 2013 - 2019 - $150 million and a Patient-Centered Outcomes Research Trust Fund, financed by transfers from two other federal medical trust funds.
Definition of PCOR

→ Patient Centered Outcomes Research (PCOR) helps people make informed health care decisions and allows their voice to be heard in assessing the value of health care options. This research answers patient-focused questions:
  – “Given my personal characteristics, conditions and preferences, what should I expect will happen to me?”
  – “What are my options and what are the benefits and harms of those options?”
  – “What can I do to improve the outcomes that are most important to me?”
  – “How can the health care system improve my chances of achieving the outcomes I prefer?”
CER vs PCOR: is there a difference?

Comparative Effectiveness Research

Patient-Centered Outcomes Research

Comparisons

Sometimes patient reported data

Not always comparative

Patient reported outcomes

Subgroups
Comparative trials are not child-focused

- In a sample of studies examining high priority areas for comparative effectiveness research (CER) between 2007-2010, less than a quarter are CER studies and the majority is supported by government and nonprofits.

- Industry-funded CER studies were associated with the fewest pediatric subjects.

- Current live trials are not answering our pediatric CER evidence needs.

Toward a Dedicated Pediatric CER Agenda

- Ensuring databases and registries include pediatric populations
- Increasing data usability, comparability, linkability
- Developing dedicated framework for translation and dissemination
- Setting life-course perspective research priorities
- Establish ongoing priority-setting process in pediatric community

PCORI Cycle I Awards: CHSR?

→ 7/25 awards focused on pediatric or adolescent populations

→ Topics included:
  – Adolescent Lipid Screening and Treatment Strategies
  – Family Navigator Services for Antipsychotic Meds
  – Shared Medical Decision Making in Pediatric Diabetes
  – Decision support for parents receiving genetic info about child’s rare disease
So What is Next?  
*The Adolescence of CHSR*

- HSR has to “learn how to learn” in order to stay relevant, timely, and rigorous
- Three forces could transform CHSR:
  1. The ever expanding sources of data, particularly prospective, electronic clinical data;

*Simpson, L. “The Adolescence of Child Health Services Research.”*  
*JAMA Pediatrics; forthcoming, March 2013.*
ARRA-CER Funding Electronic Clinical Data Infrastructure

Total ARRA-CER Funding
$1.1 Billion

- Evidence development and synthesis
- Translation and dissemination
- Infrastructure and methods development
- Priority Setting
- Stakeholder Engagement

Infrastructure & Methods Development
$417.2 Million (37.9% of ARRA-CER Funding)

- Governance
- Data
- Methods
- Training

Electronic Clinical Data Infrastructure
$276 Million (25.1% of ARRA-CER funding)

- Clinical and claims databases, electronic health records, and data warehouses
- Patient Registries
- Distributed and federated data networks
- Informatics platforms, systems and models to collect, link and exchange data
Emerging Data Resources

- Expanded Claims Data
- Electronic Health Records (EHRs) and Registries
  - Collaborative Science
- Patient Contributed Data
  - Patient Reported Information
  - Biomonitoring
  - Crowd-sourced Data
- Incidental Data
* Mashups
The Electronic Data Methods (EDM) Forum

→ Advancing the national dialogue on the use of electronic clinical data (ECD) for the conduct of:
  – Comparative Effectiveness Research (CER)
  – Patient-Centered Outcomes Research (PCOR)
  – Quality Improvement (QI)
EDM Forum: Research Networks in CER and QI

- Networks include between 11,000 and 7.5 million patients each; more than 18 million in total
- 38 CER studies are underway or will be conducted
  - Address most of AHRQ’s priority populations & Conditions
- Over 300,000 participants in the CER studies
So What is Next: *The Adolescence of CHSR*

- HSR has to “learn how to learn” in order to stay relevant, timely, and rigorous
- Three forces could transform CHSR:
  1. The ever expanding sources of data, particularly prospective, electronic clinical data;
  2. The demand by users of research for engagement throughout the life cycle of research; and

Engagement

→ Patient centered outcomes research
→ Community based participatory research
→ Policy driven/relevant research
→ Systems driven/relevant research
A Framework for Consumer and Patient Engagement

Analysis of dynamic relationships between the technical infrastructure and its use in an organizational context, which includes evolving business and technology needs as well as potential applications by end users.

So What is Next: The Adolescence of CHSR

HSR has to “learn how to learn” in order to stay relevant, timely, and rigorous

Three forces could transform CHSR:

1. The ever expanding sources of data, particularly prospective, electronic clinical data;
2. The demand by users of research for engagement throughout the life cycle of research; and
3. The need for better methods to understand quickly which innovations and improvement efforts actually work

Taxonomical Turmoil

- Improvement science
- Quality improvement research
- Implementation research
- Dissemination & implementation research
- Rapid cycle evaluation
Rapid-Cycle Innovation: Documenting and Learning

- What does the innovation seek to achieve and how? over what time frame?
- Tracking what was implemented and when vs. what was planned
- Timely measurement and feedback to innovators—on metrics that matter to them.
- Realistic expectations: implementation always takes longer than expected and more so if the context is complex
- Guidance for replication, generalizability, assessing and interpreting impact

Rapid-Cycle: Fast Enough?

- Trade-off between “rigor” and “rigor mortis”
- Avoid stifling innovation to improve system because “no data are good enough”
- Weighing Type 1 versus 2 error: how “good” are things now, how much certainty is desirable to spread or kill an intervention?
- Congressional history: Legislators have acted before evaluations are done. They have also failed to act despite evaluation results showing what was or was not successful.

Consolidated Framework for Intervention Research

→ Intervention
  – Source, evidence strength & quality, relative advantage, adaptibility, trialibility, complexity, cost

→ Outer setting
  – Patient needs & resources, “cosmopolitanism”, peer pressure, external policies & incentives

→ Inner setting
  – Structural characteristics, networks & communication, culture, implementation climate

Damschroder et al, Implementation Science, 2009
Consolidated Framework for Intervention Research

→ Individuals
  – Knowledge & beliefs about intervention, self efficacy, stage of change, identification with organization

→ Process
  – Planning, engaging, executing, reflecting and evaluating
How do we move from a field documenting and understanding

“What’s wrong?”

to a field finding out

“What works?”

“For whom? Under what circumstances?”

and learning

“How to sustain, spread and scale effective interventions?”
We Must:

- Re-engineer our data infrastructure
- Broaden focus of QI science to systems
- Listen to children and all those who care for them
- Adopt & improve rapid cycle evaluation methods
- Keep children on the national improvement agenda
Outline

- Overview of AcademyHealth
- What do we need to know?
- How will we find out?
- How will we apply what we learn?
Policy is also made by...

Educating Policymakers

Public Policymakers (External)
- State Legislature
- County Board of Supervisors
- City Council
- County/City Health Department
- School Board

Private Policymakers (Internal)
- Community-based Organization
- Corporate Employer
- Faith-based Organization
- Hospital
- Local Business

Healthier Communities

Acosta, 2003
What is Scale-Up in Health Care?

Taking Interventions to Scale

- Moving from one to a few sites to many or all
- Building systems or processes that influence behavior of increasing # of individuals, organization, or communities
  - Essential to understand contextual relationships
  - May require new policies or organizational units
- Adapting/tailoring to local context balanced with quality control (the “evidence”)
- Think about “diffusion”

Yano, 2011
Policy Levers

- Research funding and priorities
- Aligning incentives
  - States
  - Health plans
  - Providers
  - Consumers/patients
- Transparency & accountability
- ACA implementation
  - Federal & state choices
Generating Evidence to Build a Learning Health System

Policies

Evidence Generation → Health System ➔ Knowledge Management & Dissemination

Health Care & Public Health Services Delivery

Data Flow

Community

This is a transformational time!

Child Health Services Research can generate the evidence to improve health and healthcare and move it into policy and practice!

Child Health Services Researchers must keep child health on the national research and policy agenda!
The Patient Protection and Affordable Care Act and the Future of Child Health Policy

Sara Rosenbaum, JD

“Despite the complexities and the long implementation journey that lies ahead, the Affordable Care Act is a gift to child health.”
Questions?

Lisa Simpson, MB, BCh, MPH, FAAP
President and CEO