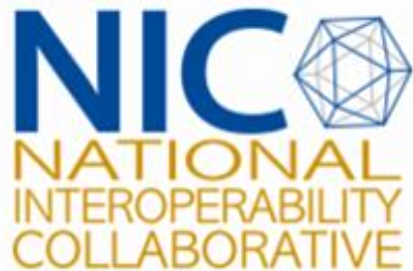




Data Collaboration for Behavioral Health Policy Implications of the CMMI Integrated Care for Kids (InCK) Model Experience to Date

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The Stewards of Change Institute is a nonprofit organization started in 2005 with the purpose of improving the futures of the most under-resourced and under-served populations by initiating, inspiring and advancing transformational change in health and human services systems at all levels of government, industry and nonprofits.

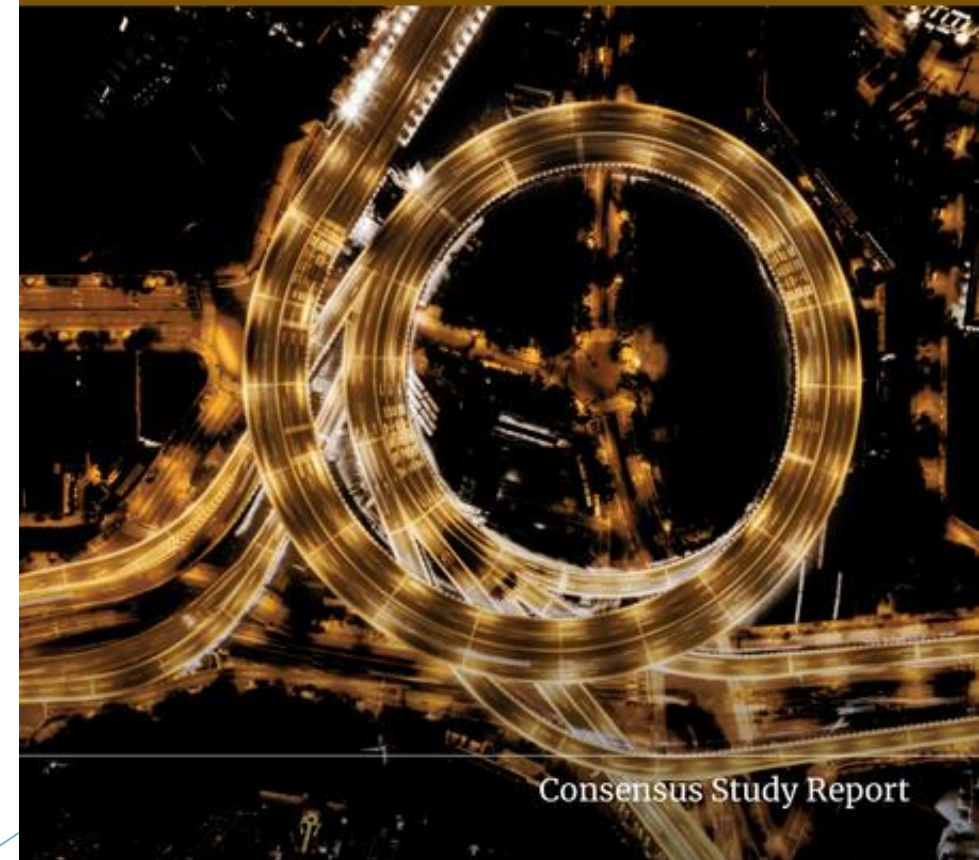
The National Interoperability Collaborative is a “Community of Networks” that increases collaboration across the spectrum of programs and sectors that enhance health, safety, education, race equity and well-being by advancing information-sharing, interoperability and standards-based technology. NIC has attracted 1,500+ members over the past 4 years, with support from the Kresge Foundation.

Key Policy Levers for Enabling Behavioral Health Disorder Prevention Efforts through Collaborative Whole Person Care

- ▶ Legal
- ▶ Ethical
- ▶ Procurement
- ▶ Data Standards

This work has no home

- ▶ AISP at U Penn can be considered the home of linked de-identified data
 - ▶ Committee on National Statistics recent report "Toward a 21st Century National Data Infrastructure: Managing Privacy and Confidentiality Risks with Blended Data"
- ▶ Linked identified data, does not have a similar funded “home”
 - ▶ Within HHS, ONC now has a whole department focus



Seeing these policy challenges through the lens of InCK



Parallels to other Processes

But where are the connections?

Children's Behavioral Health Policy Lab

- ▶ Georgia
- ▶ Kansas
- ▶ Kentucky
- ▶ Maryland
- ▶ Missouri
- ▶ Pennsylvania
- ▶ Texas
- ▶ Utah
- ▶ Wisconsin

**Child Welfare
Behavioral Health
Medicaid
K-12**

Integrated Care for Kids

- ▶ Ohio
- ▶ New York
- ▶ Illinois
- ▶ North Carolina
- ▶ Connecticut
- ▶ New Jersey
- ▶ Oregon

Full-Service Community Schools/ Promise Neighborhoods

California investing \$4.4B in Children & Youth Behavioral Health Initiative & \$4.1B in California Community Schools Partnership Program

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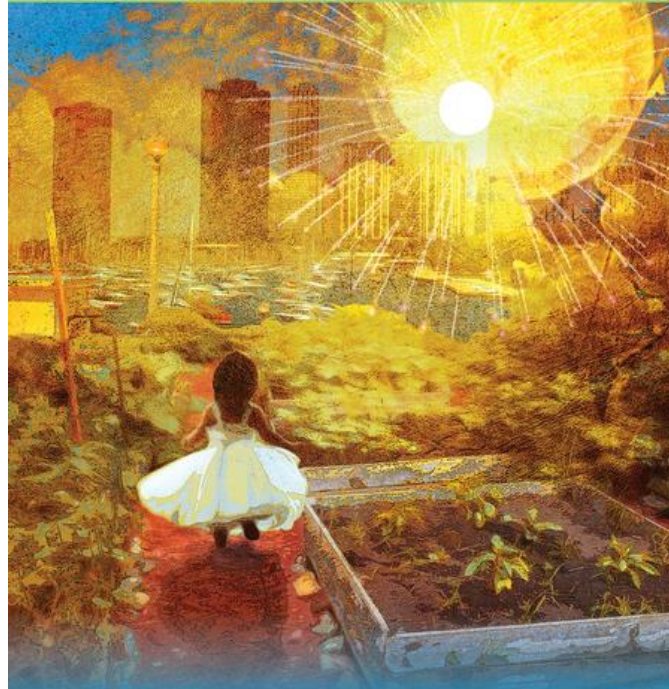
CONSENSUS STUDY REPORT

INTEGRATING
SOCIAL CARE
INTO THE
DELIVERY OF
HEALTH CARE

MOVING UPSTREAM
TO IMPROVE THE
NATION'S HEALTH

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CONSENSUS STUDY REPORT



Vibrant and Healthy Kids

ALIGNING SCIENCE, PRACTICE, AND POLICY
TO ADVANCE HEALTH EQUITY

PROCEEDINGS OF A WORKSHOP

REIMAGINING
A SYSTEM OF CARE
TO PROMOTE THE
WELL-BEING OF
CHILDREN AND
FAMILIES



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Legal Issues: The InCK Experience

State Agencies were largely paralyzed by requests from their Medicaid agency for information sharing

- ▶ Child welfare involvement
- ▶ Free and reduced-price school meals
- ▶ WIC and SNAP enrollment
- ▶ Kindergarten readiness

Legal Issues: Policy Recommendations

- ▶ Need a new “minimum necessary” standard for a Community Record
- ▶ Need consistent interpretation of federal law across states (AGs)
- ▶ Need explicit “freeing” guidance and consultation such as California’s SHIG at both federal and state level

Ethical Issues: The InCK Experience

Locally determined and guided by the Partnership Council

- ▶ # 1 Concern: Not making more trouble with justice and child welfare
- ▶ Consent for blanket sharing amongst partners vs.
 - ▶ Specific pre-defined circumstances
 - ▶ Case by case basis
- ▶ Consented information sharing is an important step toward equity
 - ▶ Removing burdensome repetitive processes
 - ▶ Preventing retraumatization
 - ▶ Improving effectiveness of services

Ethical Issues: Policy Recommendations

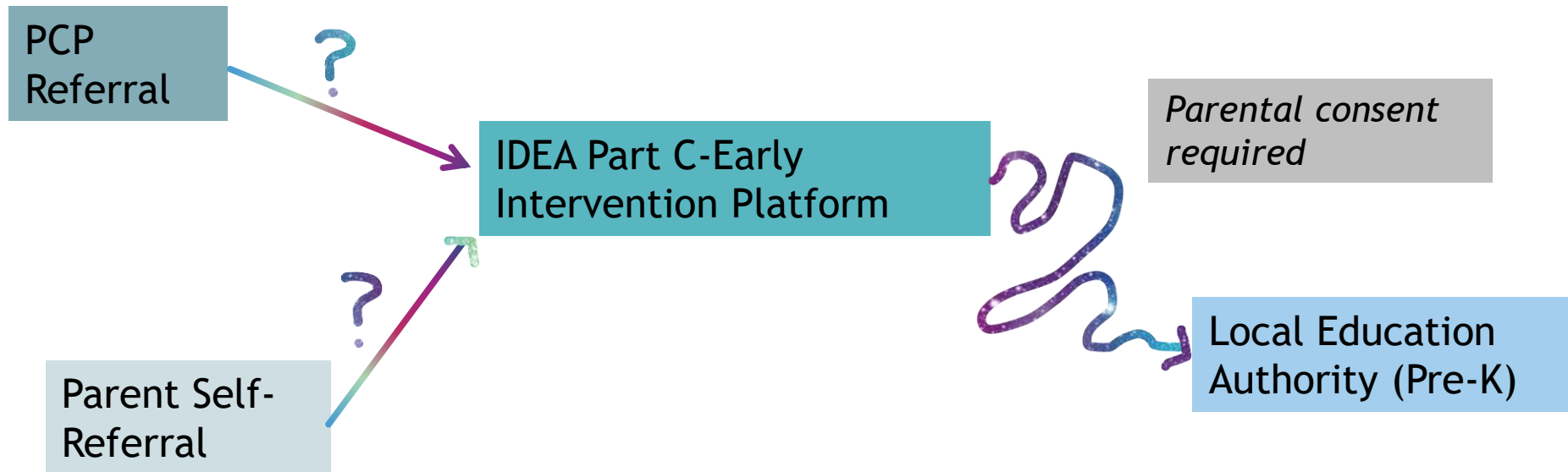
- ▶ Governance toolkit needed
- ▶ Consent-to-Share processes are essential
 - ▶ Arlington, VA
 - ▶ Western Colorado's Community Resource Network
- ▶ Additional guidance needed from the Office of Civil Rights
 - ▶ HIPAA centered guidance on disclosing PHI for social referrals not enough
 - ▶ Where can coordination cause more harm; for example by leading to CPS referrals or legal issues

Procurement of Information Systems

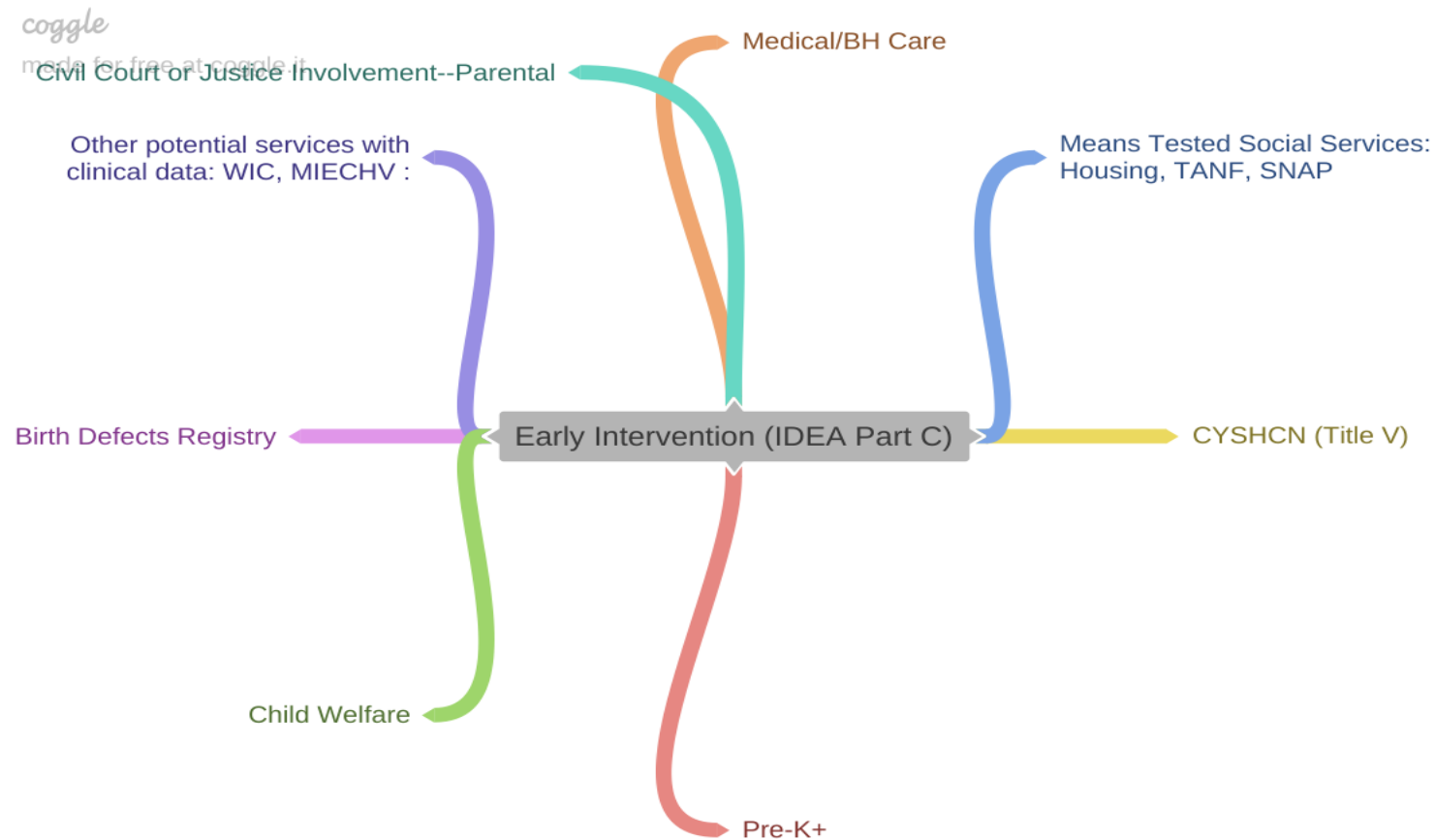
(Same principles apply to the funding of the services)

- ▶ Current health and social service systems built for essentially 2 purposes
 - ▶ Narrow workflow
 - ▶ Reporting up to county/state/federal funder
- ▶ Future systems need to be multipurpose & interoperable
 - ▶ Explicit multi-sector funding
 - ▶ Braiding and Blending
 - ▶ Cross Sector Governance: Data stewardship, ownership and usage

Information Systems Example: IDEA Part C (current)



Information Systems Example: IDEA Part C (future)



Data Standards: The InCK Experience

- ▶ CWIS
- ▶ Title V: MIECHV, CYSHCN
- ▶ CDC
- ▶ SAMHSA
- ▶ WIC & SNAP
- ▶ HUD
- ▶ Justice (NIEM)
- ▶ Education: Early Intervention, SISs (CEDS & EdFi)
- ▶ Medicine: HL7--v2 with FHIR emergent

Data Standards: Policy Recommendation

- ▶ Ensure ability to represent PEOPLE, FAMILIES, HOUSEHOLDS
- ▶ Rapidly support the new ONC role for all of HHS so that grant funded healthcare and ACF are included
- ▶ Fund, Staff and Convene cross agency working group: DOJ, USDA, HUD, DoEd etc.
 - ▶ Tie their work into procurement!

Sources of Inspiration and Guidance

- ▶ San Diego CIE/HIE
- ▶ Agency for Community Living and Community Care Hubs
- ▶ White House SDOH Playbook
- ▶ Medicaid waivers
 - ▶ NY
 - ▶ CA
 - ▶ NC
- ▶ HIEs
 - ▶ Bronx RHIO
 - ▶ Georgia HIN

Thank You

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Stewards of Change Resources

- ▶ [Consent to Share: California's Opportunity to Modernize Cross-Sector Data Sharing \(2023\)](#)
- ▶ [Modernizing Consent to Advance Health & Equity \(2021\)](#)
- ▶ [Interoperability Insights: Demonstrating the Need and the Benefits of Connecting Health and Human Services \(2020\)](#)