

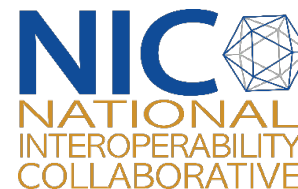
Improving Health and Equity by using a Consent Utility to Better Integrate Health and Social Care

European Social Network Conference

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Stewards of Change
INSTITUTE



Presenters



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Background



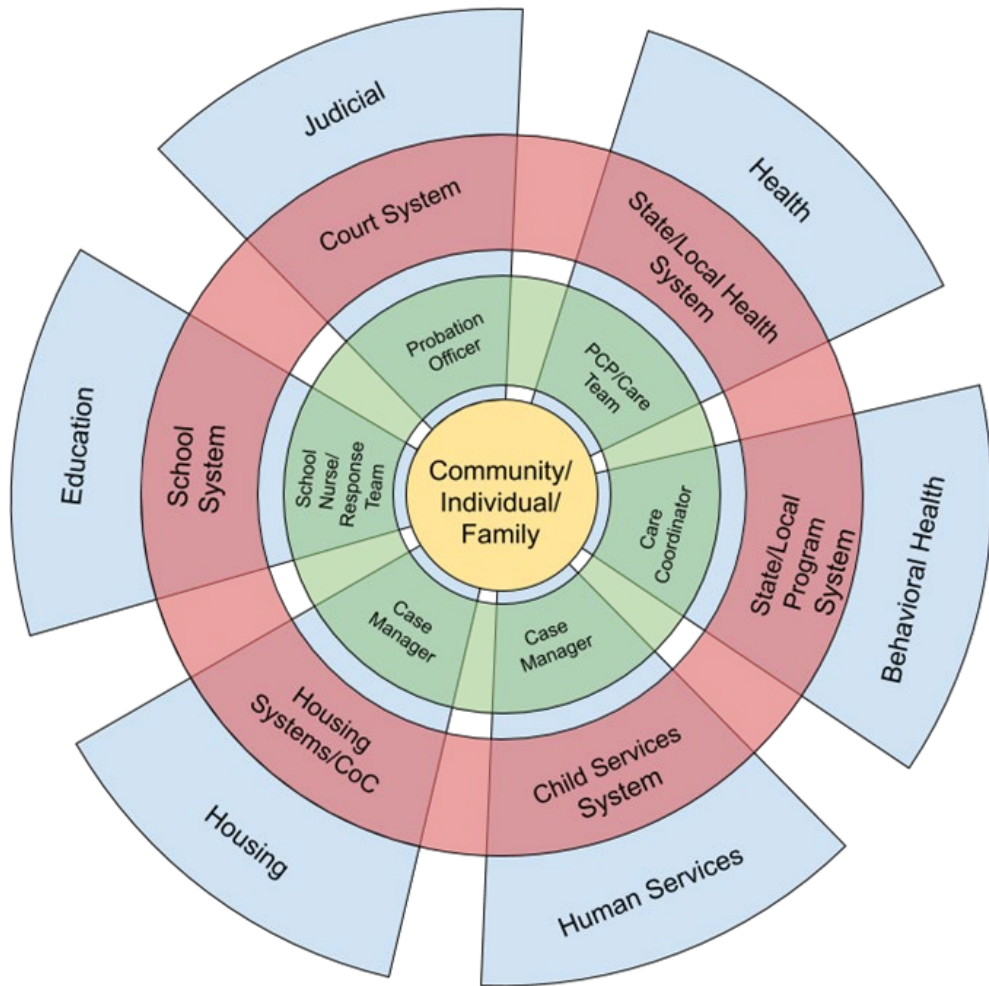
Stewards of Change
INSTITUTE

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.

A Person-Centered Approach Is SOC's *North Star*



- People need to navigate multiple systems and programs to acquire services.
- Secure, responsible, accurate and ethical data exchange is critical for decision making, care coordination, and for addressing disparities.
- New mind sets, models, tools and competencies are needed to support innovation and work across silos.

Select NIC Collaboration Partners



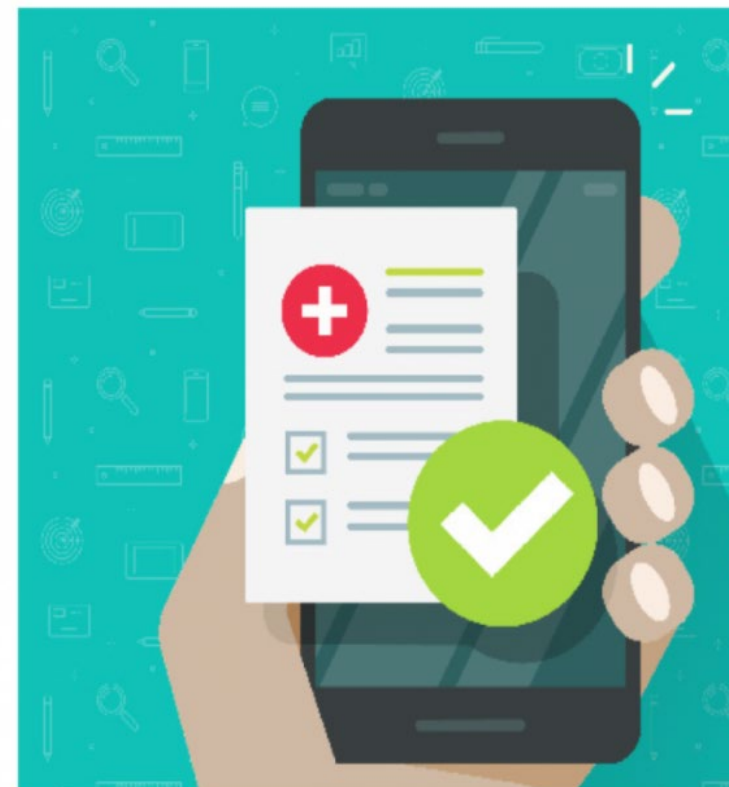
The National Action Agenda: *Advancing Upstream Social Determinants and Health Equity*

Consent-to-Share Service Utility was top recommendation from series of webinar/workshops in 2020/21 that engaged 150+ collaborator from multiple domains, sectors, industries and disciplines.

Modernizing Consent to Advance Health and Equity Environmental Scan was first action step, completed in late 2021.

Modernizing Consent to Advance Health and Equity

A NATIONAL SURVEY OF KEY TECHNOLOGIES, LEGAL ISSUES AND PROMISING PRACTICES



Basis for Creating a Consent Service Utility (CSU)

- Current information sharing consent processes are not user-friendly, confusing/complex, and do not engender trust.
- Helpers (nurses, educators, social workers, etc.) often face paper-based, non-standard processes spread across many systems, which are not accessible.
- Lack of good consent processes impedes data sharing and limits access to benefits, care coordination, and service delivery.
- This affects the most vulnerable, deepening inequities.

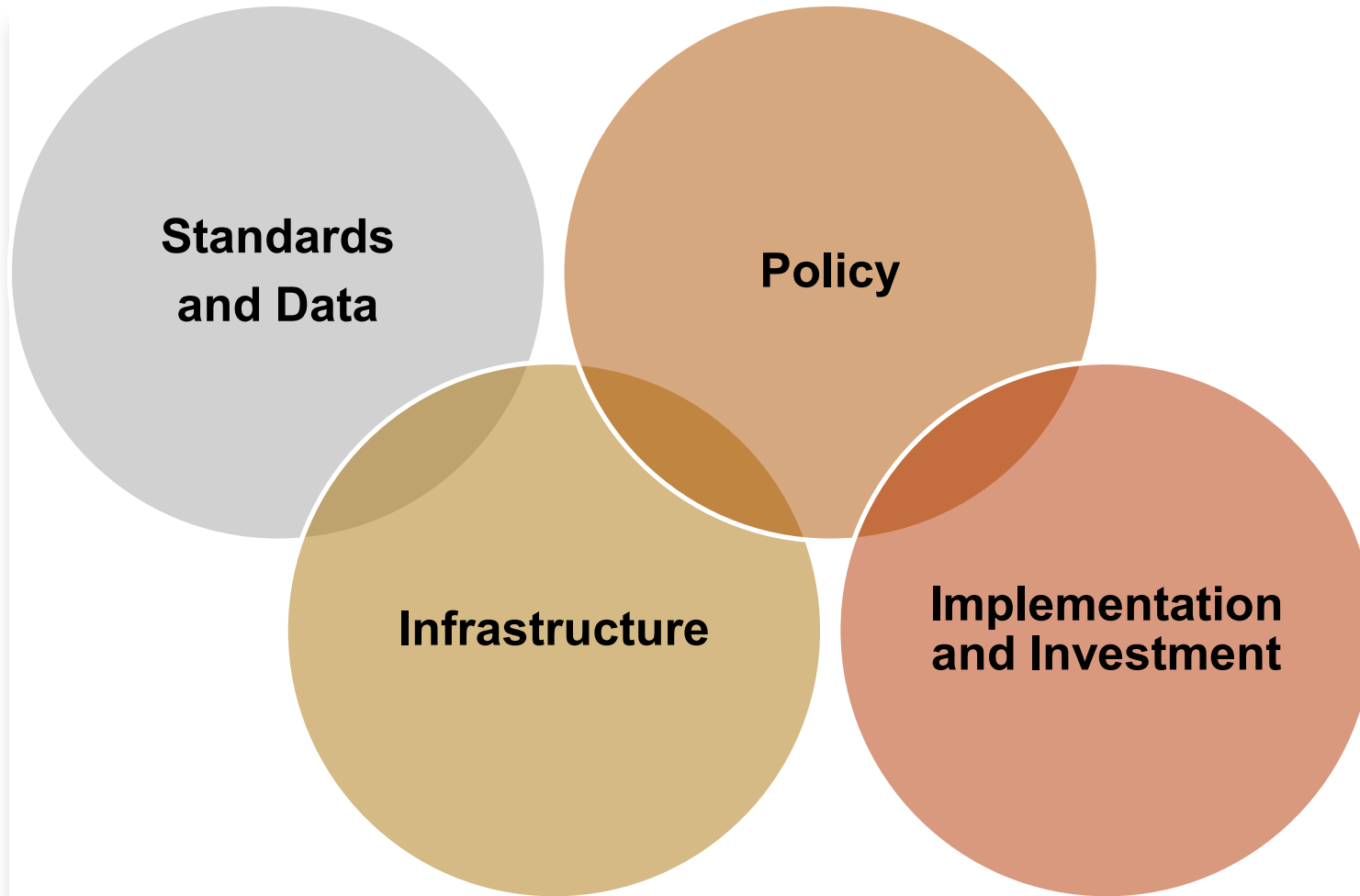
Systemic Change is Needed to Address Legal and Governance Hurdles

“In the California State Assembly, we are interested in the potential of our public systems to better serve families through local collaboration. Only recently have we begun to appreciate how our siloed policymaking, often aimed at serving the same people, can unintentionally create barriers to local collaboration and information sharing. We have started discussing how to align our policymaking to reduce these barriers and support collaboration. Stewards of Change Institute’s pilot projects that demonstrate innovative solutions to enable data sharing would help the State Assembly advance our vision of integrated systems. It could also illuminate points of friction in state law which we, as policymakers, are in a position to address.”

- Tanya Lieberman, Chief Consultant, California Assembly Education Committee

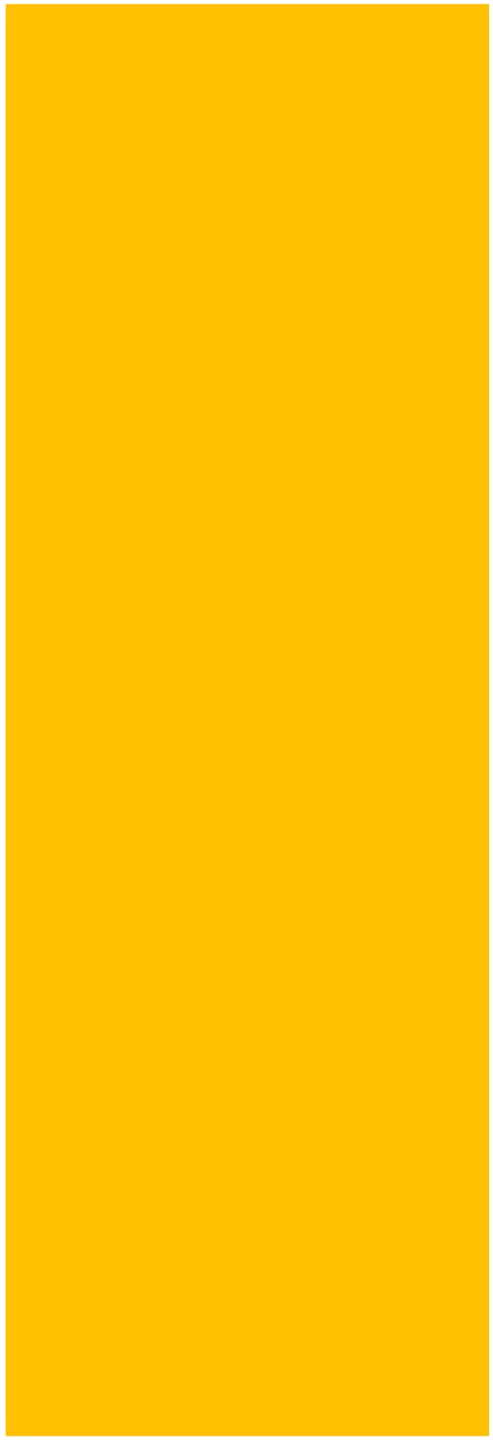
US Federal Government Data Sharing Perspectives

Micky Tripathi, National Coordinator, Office of National Coordinator for Health IT



- Convergence emerging with respect to health and human services
- Facilitating nationwide data sharing coupled with empowering individuals
- Leveraging/reusing technical design patterns to create innovative and more convenient user experiences

Video Recording by Micky Tripathi, National Coordinator,
Office of National Coordinator for Health IT (US DHHS)



Basis for Consent Service Utility (cont'd)

Goals:

- Put people in the (data) driver's seat.
- Streamline the process for both people and agency staff.
- Build trust, improve decision-making, enhance care-coordination.

Basis for Consent Service Utility (cont'd)

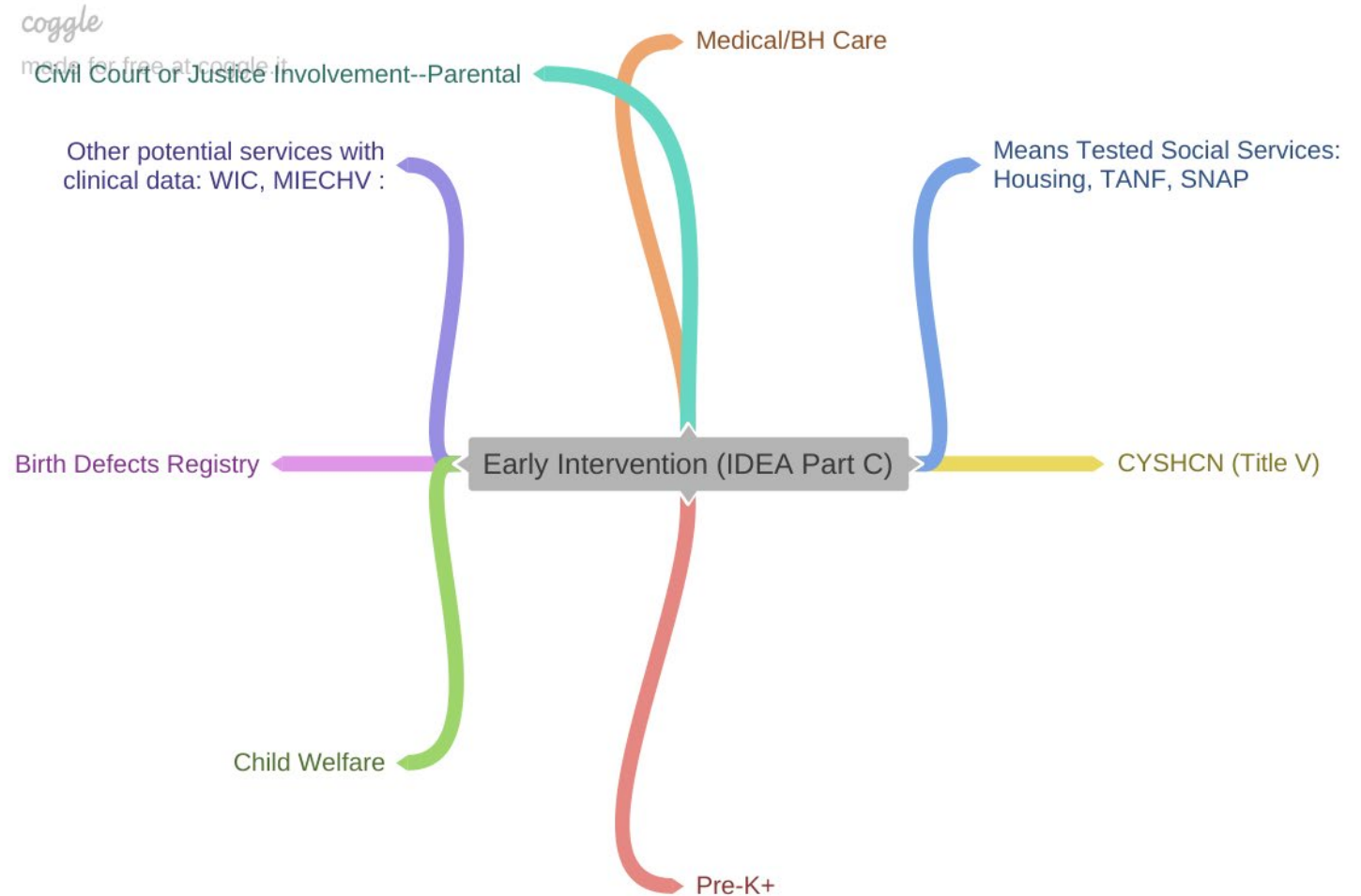
Objectives:

- Create an open-source, standards-based, proof-of-concept using technologies and promising tools to meet/exceed legal, ethical, security, and infrastructure requirements.
- Design and test a “minimally viable product” (MVP) using synthetic data, for specific use-cases and consent types.
- Apply human centered design to create a common look/feel for all consent types, and that work on all devices.
- Build a configurable “rules engine” that meet federal & state laws/policies.

Early Childhood Use Case

While multiple sites around the US are ready to participate, the initial work is with New York State as part of a federally supported program—*Integrated Care for Kids*—in the Bronx section of NYC.

Focus will be Early Childhood Systems, centered around children ages 0-3 with developmental concerns.



Technical Considerations

- Health and Social Services data is increasingly digital (though still heavy reliance on paper and manual processes).
- While health data is largely addressed by HL7 standards, other standards are needed including social services, education, justice, other data.
- Integration of consent must also incorporate individually controlled digital identity
- Identity and consent services will be provided in a mobile user experience (UX), tailored by process to limit “consent fatigue”
- Expected to align to GDPR and eIDaS2/eID Wallets
- Open-Source ecosystem to support national adoption/digital sovereignty

Discussion Topics

- Person matching
- Conversion/storage of consent documents
- User interface / human centered design best practices
 - Handheld devices vs other
 - Obtaining audio consent
 - Reviewing & revoking consent
- Legal challenges to “checklist” consent
- Application to European Data Hub to share across borders

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