Stewards of Change Institute

Public Policy Learning Lab:
Improving Consent to Share Protected Data Across the Spectrum of Care

April 17th, 2023
# Today’s Work Plan Agenda

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<th>Timing</th>
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<td><strong>10:00 - 10:40</strong></td>
<td><strong>Welcome, Vision, Goals</strong>&lt;br&gt;• Daniel Stein, President, SOC Institute&lt;br&gt;• Valerie Rogers, Director, State Government Affairs, HIMSS North America&lt;br&gt;• Stephen Konya, Senior Advisor to the Deputy National Coordinator and Innovation Portfolio Lead&lt;br&gt;• Alfonso Montero, CEO European Social Network</td>
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<td><strong>10:40 – 11:15</strong></td>
<td><strong>Ignite Sessions: Meet Our Facilitators &amp; Scribes</strong>&lt;br&gt;• Lisa Green M.D., CEO Family Christian Health Center, Chicago Illinois (Equity, Diversity and Inclusion)&lt;br&gt;• Chris Alibrandi O’Connor, J.D., Deputy Director, Network for Public Health Law – Mid-States Region (Legal)&lt;br&gt;• Brian Handspicker, CTO SOC Institute, Co-Lead Project Unify (Technology and Information Sharing)&lt;br&gt;• Kristine McCoy, M.D., M.P.H., Senior Consultant SOC Institute (Governance/Organizational Development)&lt;br&gt;• Sue Feldman, RN, MEd, PhD, FACMI, University of Alabama, Birm (Interagency &amp; Administrative Systems)</td>
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<td><strong>11:15 – 11:30</strong></td>
<td><strong>Break</strong></td>
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<td><strong>11:30 – 12:45</strong></td>
<td><strong>First Breakout Group Discussion</strong></td>
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<td><strong>12:45 – 1:15</strong></td>
<td><strong>Lunch (continue discussions/refine report-outs as needed)</strong></td>
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<td><strong>Report Out and Synthesis (3 Parts):</strong>&lt;br&gt;• Each group reports out &amp; and receives feedback e.g., clarifying questions, recommendations, (45 min)&lt;br&gt;• Each group huddles to integrate new information, update/refine recommendations (20 min)&lt;br&gt;• Final comments from each group (15 min)&lt;br&gt;• Next Steps</td>
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Thanks to State Health and Values Strategies for their Generous Support Underwriting the Policy Learning Lab

Support for this meeting was provided by the State Health and Value Strategies program, a grantee of the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.
Thanks to Gainwell Technologies for their Support for the Networking Coffee and Lunch
Thanks to HIMSS Government Affairs for Their Partnership and Support
The pandemic demanded that we think in exponential terms to comprehend the scale, rate and scope of the impending change so we could take commensurate action.
Consent Background

- In 2020/21 SOCI led *National Action Agenda* to identify actionable recommendations for systemic change.

- **Improving Informed Consent was the #1 priority** and has been our focus since January 2021.

- SOCI and colleagues researched and published a national scan of promising consent practices to serve as the foundation for the Consent Utility and several POC demonstration projects.

- **Our purpose today is to elevate consent nationally and identify substantive, actionable policy-focused solution(s).**
Three Areas for Sharing Protected Information
Adapted from ONC eConsent Discovery Workshop (8/16/2022)*
Different Types of Consent are Needed by Function

- Care Coordination and Case Management
- Research
- Public Health
- Eligibility Determination & Enrollment e.g., BDT
- Referral Organizations and 211s
We know:

- Consent is complex, requirements vary by state, program, and function.
- Processes are usually not user-friendly and don’t engender trust.
- Helpers (nurses, educators, social workers, etc.) often face paper-based, non-standard, processes across many systems, which are not easily accessible.
- The lack of standards for informed consent impedes data sharing, care coordination, outcomes, and equity.
- There is no national consent model/utility or implementation guide for states, counties, providers and industry to follow.
- Cross domain consent is no one’s job – it is the interstitial tissue between health and human services.
Today’s Goal:
- Identify audacious, actionable policy recommendation(s) that surmount system-level obstacles that inhibits cross-silo data sharing.

Why:
- Need to increase trust, center equity, improve outcomes, enhance care coordination, demonstrate viability, success and the art of the possible for others to emulate.

Longer Term Goals:
- Apply learning to the design/development of consent pilots and Consent Utility Models (NY, MN, CO, CA)
- Elevate consent nationally for HIPAA and non-HIPAA entities.
- Establish a national consent workgroup with HIMSS (and other partners).
- Disseminate Learning Lab recommendations via a white paper and social media.
## How We Plan To Accomplish Our Goal Today

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- Stephen Konya, Senior Advisor to the Deputy National Coordinator and Innovation Portfolio Lead  
- Alfonso Montero, CEO European Social Network |
| 10:40 – 11:15 | **Ignite Sessions: Introducing Our Facilitators and Perspectives**  
- Lisa Green M.D., CEO Family Christian Health Center, Chicago Illinois *(Equity, Diversity and Inclusion)*  
- Chris Alibrandi O’Connor, J.D., Deputy Director, Network for Public Health Law – Mid-States Region *(Legal)*  
- Brian Handspicker, CTO SOC Institute, Co-Lead Project Unify *(Technology and Information Sharing)*  
- Kristine McCoy, M.D., M.P.H., Senior Consultant SOC Institute *(Governance/Organizational Development)*  
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- Next Steps |
#1. Using the Thomson Family scenario and the assigned lens of your group, identify the 1 or 2 most significant obstacles that inhibit data sharing at a structural level?

#2. In what ways can improving consent practices for sharing protected information address the key obstacles and/or opportunities your group identified in Q1.

#3. What policy related changes can be realistically accomplished in 2023/24 that address the obstacles and opportunities your group identified? Longer term?

#4. Feedback and recommendations from 1st report-out.
I’m Cautiously Optimistic Because...

1. More enabling waivers (1115, 1915b) supporting Whole Person/Integrated Care (CA, OR, MA, AZ, AK)

2. Funding is available through CMCS to build/sustain consent solutions with 90/10 FFP.

3. Federal partners are aware and interested in supporting interagency consent initiatives.
   • Deputy General Counsel HHS, ACF, ONC Accelerators, others.

4. Executive Office of the President’s National Action Plan Implementation beginning in fall ‘23

5. Technological and administrative momentum:
   • Standards development, ONC LEAP CDS; Gravity Codes, USCDI, Consent-focused RFPs (WA), Industry/vendor solutions, ONC accelerators (UT Austin TX, 211 San Diego), CIEs, Universal Consent (Arlington County, VA; CA ASCMI).

6. Shovel-ready, demonstration projects through Unify
   • Bronx NY, Hennepin County, MN; Colorado, Other

7. The right people are in the room who can drive awareness, innovation and adoption
Policy Defined and Our Scope and Parameters:

| Policies that prohibit data sharing | Existing policies that can be modified | No enabling policy exists today |
Some Consent Policy Opportunities For Consideration

1. **21st Century Cures Act**
   - Potentially leverage CURES to embed and focus attention on social care data sharing as part of the new proposed rule update that is underway currently.
   - Trusted Exchange Framework and Common Agreement (TEFCA). Seize the opportunity to incorporate SDOH and social care into TEFCA now.
   - Potential action would be for this group to submit comments as part of NPRM about Consent

2. Recommend embedding Consent into one of the **ONC Accelerator Projects**, or free standing.

3. **Data Modernization** Initiative

4. Other policy Initiatives underway that you may be aware e.g., education, justice, probation, workforce, other?.

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Stephen Konya, Senior Advisor to the Deputy National Coordinator for Health IT and Innovation Portfolio Lead at U.S. Department of Health and Human Services (HHS)
Informed Consent in Social Care and Social Services

- Alfonso Lara Montero, Chief Executive Officer, European Social Network
- Chicago, 17 April 2023
Implications for Social Services

- Healthcare origins but key implications in social work
- Related to principles of self-determination, autonomy
- Needed for sharing data, recording conversations or providing interventions
- Children, People with MH problems or PwD, Frail Older People
- Variance in regulations, interpretations and applications
- Traced back to:
  - Plato Ancient Greece: “take the patient and his family into confidence … [and] does not give prescriptions until he has won the patient’s support.” Plato Ancient Greece
  - More recent case law: Schloendorff v. Society of New York Hospital case: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body.” Schloendorff v. Society of New York Hospital case
HSE Consent Policy, Dec. 2022

- Who should seek consent? The case worker is responsible & accountable
- Different interventions = each should obtain consent
- Ways to provide consent
- Refusal/Withdrawal; Capacity assessment
  - Multidisciplinary (not just healthcare)
- Principle guiding seeking consent: Best interest of the person; children (UNCRC, p. 3)
- Involving an advocate
- Role of public authorities where children/people are in their facilities
GDPR application

- Holding and processing data
- Protect privacy of individuals
- For an organisation, not just service users, also staff
- Notify of purpose and who they may need to share data with
- Appoint a data protection officer
- Provide more information about the data that’s processed
  - Differing ages of consent and provide child friendly explanations
- Consent: unambiguous, explicit and recorded
  - A local authority’s example
Concluding remarks

- Digital tools have led to further issues related to consent
- How does E-social work impact the relationship between the professional and the person?
- Ensuring valid consent requires meeting several standards internationally:
  - Not feeling pressured
  - Professionals should assess clients’ ability to make informed choices
  - Consent must be in line with the person’s right to be duly informed
  - Include the purpose, effects, possibility to refuse or withdraw, be in understandable language
  - Professionals should be trained on informed consent in digital social care and social work.
Informed consent is probably one of the clearest expressions of social workers’ respect for people’s rights to self-determination, autonomy and social inclusion.
Consent Learning Lab Ignite Presentations (6 minutes)

- Equity, Diversity, Inclusion – Voice of the Customer
  - Lisa Green M.D., CEO Family Christian Health Center, Chicago Illinois

- Legal, Privacy and Confidentiality
  - Chris Alibrandi O’Connor, J.D., Deputy Director, Network for Public Health Law

- Technology and Information Sharing
  - Brian Handspicker, CTO SOC Institute, Co-Lead Project Unify

- Governance/Organizational Development
  - Kristine McCoy, M.D., M.P.H., Senior Consultant SOC Institute

- Interagency Systems & Administrative
  - Sue Feldman, RN, MEd, PhD, FACMI, University of Alabama, Birmingham
Equity, Diversity and Inclusion

- Lisa Green M.D., CEO Family Christian Health Center, Chicago Il.

Talking Points:
- Voice of the customer for multi-system involved people.
- Silo’d systems make it more challenging for vulnerable, multi-system involved people to get care the need.
- Concerns about misuse of data collection/risk of stigmatization.
- Guard against systemic challenges, inherent socio-economic racism that inhibit equitable access to services and supports (systemic solutions are necessary).
- Access to information technology can be a hurdle for some people.
Governance and Organizational Development

- Kristine McCoy, M.D., M.P.H., Senior Consultant SOC Institute
Governance is about Creating the Interstitial Tissue

- FQHC
- WIC
- MIECHV
- Early Intervention & CYSHCN
- BCC Cancer Screening
- HIV/Substance Use
- Public Health Nursing
  - MCH
  - Homeless Mentally Ill
Applying this Challenge to the InCK Core Child Services

**CMMI Integrated Care for Kids Initiative**

**Core Child Services**
Lead Organizations will coordinate the integration of the following Core Child Service types, some of which may or may not be covered by Medicaid. Lead Organizations may consider including other child service types as appropriate.

- Clinical care (physical and behavioral)
- Early care and education
- Title V Agencies
- Schools
- Housing
- Child welfare
- Food
- Mobile crisis response services
Our Goal is to Recreate this Word Image Reflecting Governance of Information Needed for Integrated Health and Human Services
Technology and Information Sharing

- Brian Handspicker, CTO SOC Institute, Co-Lead Project Unify

Key Points:
- Socialcare needs data sharing within and across silos – requiring a focus and practice on interoperability standards;
- Sharing socialcare information is different than sharing healthcare information;
- Consent Utility model(s) and implementation guides can enable jurisdictions to more rapidly replicate and customize consent solutions to their specific needs/legacy (to accomplish care coordination, not just closed loop);
- There is promising/emerging work happening, progress is possible, but national/federal help/guidance is needed to minimize duplication and avoid fragmentation.

- Demo of an example in the IHE Interoperability Showcase Tuesday 1:30-2:00.
People generally must navigate multiple domains, systems and programs to acquire critical socialcare services and supports.

Secure, responsible and accurate information exchange is crucial for decision making, treatment, oversight and knowledge management.

Gaining Consent is first step for exchanging PHI/SSI.

New mind sets, models, tools and competencies are needed to work effectively across silos.
Sharing Social Information Other than Medical/Clinical
Consent Utility Models and Implementations Enable

Source: San Diego LEAP-CDS (https://github.com/sdhealthconnect/leap-cds)
Consent-mediated SDOH Referral Demonstration

**PRAPARE Survey App**

- Consent-mediated FHIR Questionnaire/Response
- Electronic Health Records System
- Socialcare Case Management

**Food Insecurity (SNOMED 733423003)**

**Socioeconomic**
- Physical Environment
- Health Behaviors
- Health Care

- Condition – Health Concern: Food Insecurity (SNOMED 733423003)

**State SNAP Agency**

- FHIR Task/ServiceRequest or 360X over Direct or Fax or Print/Post Referrals

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**EQUAL HOUSING OPPORTUNITY**

**Housing Choice Voucher**
Chris Alibrandi O’Connor, J.D., Deputy Director, Network for Public Health Law – Mid-States Region

Background:
There are many laws that govern the balancing of privacy rights with the need to use or disclose (share) personal health information; each law has a legal framework for when consent is/is not needed.

Problem:
See above.
Solution:

- Addressing and redirecting the “culture of ‘no’”
- Policy changes:
  - Greater clarity and synchronicity of health data privacy laws
  - Adoption of consent standards for the sharing of health information: Voluntary, Informed, Understandable, and meeting Competency requirements
Sue Feldman, RN, MEd, PhD, FACMI, University of Alabama, Birmingham

Key Points:
- A “systems” approach is needed to change perspective, dialogue and various audiences – all needed to accomplish whole-person care and social good to succeed
  - Move from systems thinking to systems practice
  - Procuring Interoperability
- Changes within and across systems/organizations are needed to make change
- Technology can help facilitate Whole Person Care.
## Breakout Facilitation Teams & Scribes

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<tr>
<td>Adam Pertman</td>
<td>Ivy Pool</td>
<td>Robby Franceschini</td>
<td>Ben Schooley PG Forest</td>
<td>Pooja Babbrah</td>
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<tr>
<td>Stephanie Thornton (Scribe)</td>
<td>Alana Lerer (Scribe)</td>
<td>Evan Dunne (Scribe)</td>
<td>Shehirbano Akhtar (scribe)</td>
<td>Pooja Babbrah (Scribe/TBD)</td>
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Facilitator Guide for Breakout Groups

- First Breakout (75 minutes)
  - Facilitators: welcome, review goals and the group’s lens (10 min)
  - Rapid individual Introductions (10 min);
  - Discuss Thomson Family situation; frame key challenges/opportunities. (15 min)
  - Identify 1 – 3 significant hurdles that inhibit cross-domain data sharing, care coordination; discuss the role/impact of consent; consider your group’s lens; discuss how a consent utility could address the challenges. (30 minutes)
  - Capture responses on worksheet that articulate policy, group’s perspective, actors and needed actions, timing (10 minutes)

- Box Lunch (30 minutes)

- Iterative Breakouts (80 Minutes)
  - Each group report outs using template; solicit response e.g., clarifying questions, recommendations, epiphany, parking lot (30 min)
  - Each group huddles again to review, synthetize and integrate feedback; update recommendations on new template (30 min)
  - Final presentation including actionable recommendations from each group (20 min)
Meet The Thomson Family...

- What’s going on with the family and individuals?
- What and how many systems do the Thomsons interact with?
- What’s it like for this family to get help?
- Whose stories/personas does your group gravitate towards most strongly?
- Key obstacles (family, personas)?
A 10-year-old boy named Jameson has recently been placed into the child welfare system because his single mother, Sarah Thomson, was incarcerated for driving under the influence of opioids and reckless endangerment. Her car was totaled when she crashed into a light pole. As a result of her arrest, Child Protective Services placed Jameson and his 3-year-old sister, Madison, in the legal custody of Sarah’s mother, Ruth, while social workers and the courts decide if either or both children will be reunited with Sarah, remain with their grandmother, or move to a foster family to await adoption.

Sarah, who is 29, was between jobs and cannot afford to buy a new car. The social service professionals now working with her (primarily at the drug rehabilitation facility where she is currently living) worry that it will be difficult for her to find another job once she’s out of treatment, especially in the midst of the coronavirus pandemic. They are also concerned because, even if she finds employment, there is virtually no public transportation in the area in which she and her children have been living with her mother. Sarah is a medically complex patient with multiple chronic conditions: asthma and kidney problems that put her at risk of progressing to end-stage renal disease. She is also under court-ordered Medication Assisted Therapy for her opioid addiction.

Jameson, Madison and their mother moved into Ruth’s subsidized apartment six months ago, after Sara divorced the children’s father, John Thompson. He is a military veteran who is currently homeless; he provides no financial support to his ex-wife and children.

The family’s total income – including Ruth’s – barely exceeds the federal poverty level, so they receive TANF, SNAP and Medicaid benefits. Ruth’s apartment is in a rundown area of town, a “food desert” with few services such as public transportation. A furniture manufacturer and a large corporate farm in the area have contributed to air and water quality issues, and several lawsuits have been filed against them alleging that their activities undermine the health of local residents.

As a result of the family’s problems and Jameson’s transfer to a school near his new residence, he was held back a grade, a reality that is taking an educational, emotional, and social toll on him. Jameson is receiving behavioral health therapy, prescribed by Child Protective Services to address his Adverse Childhood Experiences, which include his parents’ divorce, his father’s complete absence, his mother’s addiction and incarceration, his moves to a new community and school where he knows no one, and regular taunting by other children – and sometimes adults – related to his being biracial. (He presents as Black, like his father, and the neighborhood in which he lives is overwhelmingly White.)

In short, Jameson is traumatized. He is also dealing with new, challenging experiences such as meetings with an overloaded case manager, appearances in family court, the stress of both his parents’ absence, and becoming accustomed to a new primary care-giver and residence. And, at the same time, he has been detached from his entire support system except for his grandmother, who takes two buses every day to travel for over an hour to her job cleaning hotel rooms; as a result of COVID-19, her hours there have been cut from 35 to 15 per week, resulting in a major loss of income.

Jameson has become withdrawn at school and testy with his grandmother. Since he moved in with her, he has not been regularly taking his medications or using his inhaler, as a consequence, his physical, mental, and behavioral health are deteriorating. In addition, although he has an IEP and receives behavioral health therapy, Jameson has connected with some older kids in the neighborhood and occasionally uses drugs and alcohol as an escape from his misery and anxiety. His new teachers see his steady devolution and provides a mandatory report to the Student Study Team. The team then contacts his child welfare case manager, who needs to work with Jameson’s primary care physician, a psychologist, teachers, foster parents, and a family court to get him additional behavioral health support/services for his trauma, substance abuse, and other issues.
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