Realizing the vision of whole-person care, informed by the Social Determinants or Drivers of Health requires upending our focus from a narrow definition of health to a more inclusive, holistic view, as first codified by the World Health Organization in its constitution in 1946. Toward that end, we need to keep in mind the complex and nuanced conditions and situations experienced by the individuals and families at the heart of our efforts. A systems approach that seamlessly stitches together the current patchwork of siloed programs and agencies is needed to make meaningful progress on their behalf. Coordinated care will likely shift expenditures currently concentrated on low-value biomedical care to higher-value types of care across the health and human services continuum of care in order to improve outcomes.

Today, it is challenging to even envision this future state due to our lack of a comprehensive understanding of people’s needs, the services they do and do not receive, and the resulting outcomes when a prerequisite need such as affordable high-quality food is not met for a person with a chronic diabetes or a child whose growth trajectory is shifting from healthy to concerning. The policy challenges surrounding these issues are complex, but change is achievable, and the tools, technologies and knowledge needed to surmount those challenges and accomplish the needed change are already within our grasp.

For almost two decades, Stewards of Change has worked to make progress on these questions through an array of regional and national convenings, collaborative forums, consultation, thought leadership activities, and on-the-ground initiatives. We have focused on identifying the key enablers and inhibitors as well as the environmental trends that impact data sharing and interoperability. At the end of 2022 we were invited by the Executive Office of the President (EOP) to share with them key policy challenges that we have crystallized and which are amenable to change through consistent leadership, bold innovation and broad system alignment. The EOP has developed and is now planning the implementation of a national action plan to integrate deliberate processes to address social determinants across federal agencies.

The following four policy areas provide a starting point for our discussions during the Learning Lab, the goal of which is to identify the key policy drivers that if changed can dramatically improve consent management across the spectrum. We hope they provide a common starting point so that we can quickly, delve deeply into the critical inhibitors and potential solutions that can fuel progress during and after the lab.

Addressing the challenges of informed consent for sharing protected information is our first policy recommendation to the EOP (and everyone else). It is also the key focal point of the Learning Lab. Consenting processes are central to enabling (or more often inhibiting) data sharing, system interoperability, decision support and care coordination – each of which are all vital for improving operations, outcomes and equity.

1) A lack of policies enabling whole-person care, including facilitating eligibility and enrollment processes, by explicitly recognizing, endorsing, and facilitating processes for ethically and efficiently obtaining and managing individuals’ consent for legal information-sharing across sectors and programs.

   a) Clear, facilitative federal policy guidance to state officials, and parallel state guidance to counties and municipalities responsible for enacting or supervising federal and/or state funded programs,
along with professionals and organizations in medicine, public health, human services, education, justice, etc. specifying the “could,” “should,” and “must” of data sharing for comprehensive care.

b) Clarification of existing federal privacy standards is needed to ensure they are interpreted consistently across the country. (e.g., Can/should/must SNAP or Medicaid enrollment data be reused to facilitate eligibility and enrollment in other programs?) This will facilitate the ability of privacy officers and data-governance bodies to rapidly eliminate federal and state barriers to data-sharing where they do not truly exist and to put proper mechanisms such as individual consent and/or data sharing agreements into place where not obstructed.

c) Guidance is needed regarding the use of “plain language” in documents that is appropriate for the purposes of equity and inclusion, and best processes for service agency staff to facilitate informed-consent decision-making to enable individuals to choose whether to enable or restrict the sharing of their sensitive personal information (PII, PHI, etc.).

d) Sustained governmental and philanthropic support should be provided for open-source, replicable technology solutions that enable obtaining, managing, and revoking informed consent, especially for coordination and consolidation of people’s care plans across clinical programs, social services, education, justice, public health and/or others. This approach is necessary to lower the barriers to entry and reduce the risk of worsened inequity resulting from proprietary consent systems and additional closed systems of information.

2) A significant lack of interoperability standards, approaches, and technologies across the multiple domains, sectors and programs serving health and human services across the nation.

   a) Federal encouragement and incentives are needed to spur and accelerate public and private investment in national standards development, testing, adoption, and utilization. Recognition that sectors have already committed to various standards (e.g., FHIR/HL7, NIEM, EdFi) and investment are needed to harmonize and cross-walk the various ontologies, creating both consistent, verified, reusable translators between systems and guidelines for reconciling disparate data from multiple sources.

   b) Innovative Federal and state procurement requirements are needed to drive purchase, development and adoption of systems to employ these interoperability standards and to ensure existing and new systems can readily adapt to evolving technologies and standards.

   c) Federal and state policies need to be coordinated to guide the ethical development and use of natural language processing and artificial intelligence to capture and use unstructured (narrative) data, which is generally buried in case notes and other untapped information sources, and which can augment the 360 views of persons, including their existence in families and household, needed for holistic care management.

3) A lack of appropriate IT investments and flexibility for blending and braiding funds across sectors. Specifically, there is a lack of IT investment in cross-sector coordination to minimize the burden on individuals and families requiring multiple levels of support who typically have the most inequitable outcomes.

   a) The ONC, through its coordinating committee, and/or other federal agencies with whole-of-government coordination responsibility, should – with intentionality and some fanfare – instigate, promote and support the development of user-friendly utilities that can be used to execute, store,
retrieve and alter individual consent documents to facilitate the appropriate sharing of sensitive
information.

b) ONC’s role, mission, funding, and work should be formally expanded beyond “health care IT” to
enable the agency to explicitly incorporate human services and other non-health IT programs
related to human well-being.

c) New procurement models are needed that are designed to accommodate enterprise-wide solutions
that cross-cut health, human services, justice, education, and other services that affect impact
human well-being.

d) Affordable, open-source code base tools should be encouraged and be reimbursable through
federal investments. (One example is the Omnibus Care Plan originally developed by SAMHSA, now
evolving into ACF’s Operation Data Hub.)

e) States should be encouraged to build systems that facilitate bi-directional data exchange between
multiple state and county systems. In states that employ a state-supervised and county-
administered approach this requires special attention to county level procurement and governance.
A good model is San Diego’s ConnectWell system, which operates across public health and human
services; and which is now being connected to both the region’s Community Information Exchange
system and Health Information Exchange system.

f) Cost-allocation and consolidated-reporting requirements need to be reconciled to allow federal
investments to be leveraged to support as many people as possible. One example is to update and
reinstate the A87 cost-allocation waiver, enacted during the initial PPACA implementation.

g) Federal agencies should be encourage and/or incentivized to adopt language in their annual FOAs
that enables the mingling of funds across programs/agencies explicitly to build data/technology
systems to share data, adopt/use data standards, and implement interoperability.

h) At all levels, better care coordination and navigator services need to be funded across domains to
address the range of family and/or individual challenges and/or build on strengths. This will enhance
proactive approaches to “internal” issues such as intra-family relationships and facilitate effective
use of “external” systems with which family members often interact collectively, such as housing
and nutrition supports.

4) Lack of systems-level training, planning, piloting, and implementation for policy makers, executives, and
program implementers.

a) System-of-systems engineering thinking, planning, and training should be incorporated, offered,
incentivized, and utilized to facilitate the planning and development of cross-silo, enterprise-wide,
whole-person care initiatives.

b) Education and guidance are needed to recognize and accommodate the important roles and unique
challenges counties play in states in which health and human services programs are state-supervised
and county-administered. (Nine states fit into this category for child welfare, accounting for 35% of
the US population.)

c) Community-based organizations – which deliver a highly significant portion of federal, state and
county-funded programming – need both better support for overhead costs, including information
technology, and related liability coverage. They also need direct access to the data they generate on
behalf of those programs, in order to create local cross-sector enterprise systems and to expedite
community-level analysis and process improvement.
d) Policies and practices should ensure the inclusion of the legal system in any programming focused on health and well-being. Both the civil and criminal legal systems have tremendous influence on people’s lives, so improving other agencies’ understanding of their operations can lead to both preventive and palliative innovation, with careful attention to sharing information only when required by law or consented to by the persons involved.

e) Endorsed cross-domain governance models, including model legal agreements, are needed. Federally approved models and processes are necessary to efficiently enable decision-making and/or resource-allocation across programs, systems, and domains. (At present, decision-making about cross-domain information-sharing and blending funding streams serving the same clients either do not get off the ground or are delayed for years while governance models, MOUs and DUAs are negotiated from scratch again and again with successive leadership changes.) A good example of a model is the enterprise-wide Data Sharing Agreement enacted recently by the California Health and Human Services Agency for all programs, as part of their whole person MediCal waiver program.

f) Very importantly, mechanisms need to be created, promoted and broadly utilized to engage people with lived experience throughout programs and projects to remediate racial and socioeconomic disparities, as well as to advance health equity. Federal policies need to enable fair compensation for the time and efforts of such community consultants, who are critical to program design and ongoing operations and evaluation. Vitally, this effort should include the provision of child or elder care, as well as nourishment, when needed.

Recommended resources that delve more deeply into some of the topics outlined above include:

- Modernizing Consent to Advance Health and Equity: A National Survey of Key Technologies, Legal Issues and Promising Practices (Link)
- In The NIC of Time: Six Domains of Primary Focus for the National Interoperability Collaborative (Link)
- National Action Agenda Symposium to Advance Upstream Social Determinants and Health Equity (Agenda Link, Summary of Action Recommendations Link);
- Office of the National Coordinator - Discovery Workshop on eConsent: From Birth to End of Life (Workshop session summary LINK)