Role of data in transforming health and human services

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In King County, WA, there is a broad understanding that health begins where we live, learn, work and play. Because of this, we know we must work differently, if we are to achieve better and more equitable health at lower costs. Multiple sectors, including but not limited to healthcare, behavioral health, managed care organizations, public health, housing, social services, and community-based organizations, are now partnering in a countywide transformation initiative that aimed at creating an accountable and integrated system of health, human services, and community-based prevention.

This transformation requires new levels of coordination and collaboration and a pressing need for data. Data are needed for planning, monitoring, and evaluation purposes. At the front-end, data is needed to assure that transformation efforts are data-driven and targeted. At the back-end, data is need to measure progress and to assure that desired outcomes are achieved.

Transformation efforts are targeted at both the individual and population level. For instance, at the individual level, providers are seeking data that supports the provision of "whole person care". This requires both historical and current data that provides insight on the supportive or detrimental factors that impact an individual’s health. At the population level, linking multi-sector data is viewed as essential for working at the intersection of sectors (e.g. housing and health). At both levels, having timely, easily accessible, quality data are desired.

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Many challenges will have to be overcome to achieve this vision of shared actionable data. Just within the healthcare system there are challenges related to data fragmentation, the lack of interoperability, and differing policies governing the use of medical and behavioral health (i.e., mental health and substance use) information. As transformation initiatives focus on working at the intersections of health and other sectors such as housing, education, or criminal justice, new sets of challenges arise in terms of data governance, data privacy and safety, and data sharing. And of course, there is the challenge of working with resource and finance constraints.

Since mid-2015, the King County’s Accountable Community of Health Performance Measurement Work Group (PMW, kingcounty.gov/PMW) has been convening stakeholders that include data owners, data analysts, IT specialists, data privacy officers, and data users to support and realize data sharing and integration for the purpose of supporting the transformation of health and human services in the county. The PMW includes representatives from local and state government, managed care organizations, providers, and other interested stakeholders. Regularly bringing together the various actors and entities who have a vested interest in how data is produced and utilized has been critical to understanding the differing lens and perspectives on data sharing.

As the PMW has met, several key issues have arisen that may be useful for others to pay attention to as they embark on addressing data needs of health and human service transformation efforts:

**DATA GOVERNANCE** provides the structure and process from data collection to utilization of the data. Particularly when multiple sectors or partners are engaged, early agreement on the business case and value proposition for data sharing is critical. It is not surprising to find differing perspectives among sectors. For instance at a high-level, from a public sector perspective, data is a public good. In contrast, for private entities, data is a commodity or a valued asset. The shared goal of delivery system reform that includes Medicaid incentive dollars has kept our partners at the table.

**DATA PRIVACY AND SECURITY** underlies all agreements related to data sharing. Federal and state regulations define protected health information, and dictate access to specific types of data such as mental health, substance use, and communicable diseases. In addition, institutional policies and practices often define what and how data are shared. We heard repeatedly that privacy and security officers want to be engaged early in the development of projects versus being asked to help with data agreements after the conceptual phases of project are complete.

**TECHNOLOGY AND INFRASTRUCTURE** advancements are occurring at lightning speed. There is no one right solution or approach to data systems or solutions. Whether it is figuring out data storage, data analytics, or data visualization tools, the elements of time, resources, and capability all come to play. Critically, there is an opportunity to create efficiencies when there are multiple stakeholders or partners interested in the same shared data. Keeping the larger vision in mind while taking an iterative approach (e.g., starting with efforts to link Medicaid administrative data to public housing data) allows for work to proceed and progress to be made.

**RELATIONSHIPS** are the foundation of data sharing. For instance, in efforts to improve the health and well-being of low income housing residents, King County Housing Authority and Seattle Housing Authority are working with Public Health – Seattle & King County to link public housing administrative data to Medicaid claims data. For the housing partners, it has been important to them that the public health epidemiologists learn the basics about low-income housing and to be able to communicate in “housing speak”. This serves as the basis for trust, and will be critical as both housing and public health examine and use the data to better serve this vulnerable population.
Just as we are seeking a transformation of health and human services, so too are we seeking a transformation of data and data systems. Unlocking the potential of shared actionable data necessitates collaborative partnership from those who are the data creators to the data consumers. If we work together, our short-term data goals will indeed help to drive our long-term goal of health equity and well-being.

Providing the right people the right information at the right time can promote evidence-based decision making for health policy and programs. By making available a current, fuller picture of health and well-being at the individual and community level, decision makers will be better able to both gauge and make progress towards our collective goals.

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