
POLICY BRIEF -- PERSPECTIVES ON DATA EXCHANGE

For the past two years Health & Medicine’s Center for Long-Term Care Reform has worked with a Learning Collaborative of providers, consumers, and payers to identify actionable strategies to improve integration of behavioral health and primary care. From early planning conversations that set the stage for the Learning Collaborative to recent planning to test new methods for hospital transitional care, data exchange has consistently emerged as a major challenge to implementing integrated models and improving services for people with mental illness and substance use disorder.

The Learning Collaborative recognized that Health Information Technology (HIT) and data exchange were key components of integrated care, which is reflected in the six criteria we agreed upon in our first year. The six criteria identified the components that a model must include to be meaningfully “integrated.” Technology and data exchange became a criterion for integration because much of the work of connecting the existing behavioral health and physical health silos depends on sharing information and improving communication between providers. But data exchange also arose as a central challenge to fulfilling each of the other five criteria as well, as explained below.

The Six Criteria

An integrated behavioral health-primary care model is:

1. Person-Centered,
2. Evidence-Based,
3. Financially Sustainable and
4. Provides Core Services with
5. Workforce Standards and
6. Technology Standards

To take any of these criteria seriously requires careful consideration of the role of data exchange:

- **Person-Centeredness:** All of the data collected concerns the consumer receiving services, and decisions about how and when to share this information may help or harm that person. Sharing information can also have financial and operational consequences for health care organizations, but in a person-centered model, the consequences for the consumer is primary. Therefore, truly integrated care must have established methods for building trust and engaging consumers in all aspects of their care, including the personal decision to disclose a mental illness and information sharing and communication between providers.

- **Evidence-Based:** Evidence-based practice integrates three kinds of data to provide high-quality, person-centered services: clinical expertise/expert opinion, external scientific evidence, and client/patient/caregiver perspectives. Information Technology (IT) systems that can collect, analyze, and transmit all three kinds of data are necessary to generate evidence for integration models, but on their own are not sufficient. No matter what technology and data systems are used, it is health care workers who interact with consumers to collect information on health and functional status, health-related social needs, demographics, goals, and preferences, which all go into health records, service plans, and continuous quality improvement dashboards. The important skills of engaging and building trust, as mentioned above, are crucial and can make the difference between usable evidence and meaningless noise.
- **Financially Sustainable:** Data exchange infrastructure is a major investment for upfront purchasing, implementation, workflow changes, ongoing maintenance, upgrading, and staff training. Even making the decision between the many data exchange solutions on the market requires technical expertise that is not always available in-house at a health care provider. The wrong IT system may not communicate with vital partners and delay claims submission, which are often a source of revenue; while the right IT system that is carefully implemented can support coordination of care, reduce duplication and errors, as well as optimize billing, contracts, and quality reporting.
- **Core Services:** Many of the core services in an integrated care setting entail a high level of communication between medical, behavioral health, and social service providers. Even making a referral to a service requires collecting and transmitting information or data between organizations. More advanced care coordination that can improve transitions between inpatient and outpatient care or between primary care and mental health specialists, for example, depends even more upon the collection and *timely* transmission of information between providers, often mediated by a managed care organization.
- **Workforce Standards:** One of the major challenges for providers implementing new HIT systems is the change in workflow that accompanies the shift from paper to electronic records, the use of computerized physician order entry, and the tracking and monitoring of processes and outcome, to a name a few. For example, how will the demands of electronic health records—including data entry, responding to alerts, and obtaining and managing patient consent to share information—alter interpersonal dynamics among clinicians, other staff, and consumers? Another key decision that any model should make is how peer support workers will be utilized to help consumers understand the consent and information sharing process while also building engagement in the overall plan of care.

Three Perspectives

Much depends on getting the data exchange piece of the integration puzzle right. But that puzzle piece looks different based on one's perspective. The Learning Collaborative has encountered at least three perspectives from which to view this challenge:

1. Technical challenge for providers, payers, and government agencies
2. Practice culture challenge for primary care and behavioral health providers
3. Trust challenge for consumers weighing the risks and benefits of sharing personal information with multiple individuals and organizations

Technical challenge for providers, payers, and governments

This is the perspective that is most familiar to people in the field of health care and health informatics. Physical health care and behavioral health care providers collect different kinds of information for various purposes, and are subject to many types of regulations and reporting requirements. Broadly speaking, physical health care providers collect information to populate *medical records* and behavioral health providers collect information to populate *case management records*. Both rely on data systems for billing and quality reporting, but codes and outcome measures differ markedly. When the two systems, even if they are each quite advanced, exist in such different operational worlds with staff who speak such different languages, then the ideal in integrated IT—a shared care plan that can facilitate accurate, real-time communication between integrated team members across the continuum of care—becomes a more and more distant goal. In the meantime, workarounds that require double entry or physical transfer of paper records create risks for errors and add burden to an already stressed workforce.

However there is promise in these workarounds evolving into more permanent solutions for integrated data exchange, *if* the on-the-ground lessons are heeded by policy makers who can guide decisions to invest in the public information exchange infrastructure which can bring interim solutions to scale. In the past such public investments have excluded important sectors, as when incentives for implementing electronic medical records in the 2009 HITECH Act excluded behavioral health providers.¹

The Learning Collaborative is currently conducting a hospital transitional care feasibility study to identify replicable processes that can improve the coordination of care after an individual is discharged from a hospital with a behavioral health diagnosis. Two major data exchange problems in the current hospital transitions landscape have arisen during the planning stages of the study:

1. There is no clear assignment of roles for identifying whether a patient hospitalized for a behavioral health condition has an established primary care relationship, recording that PCP's name and contact information for the Care Transitions Record (CTR), or creating a plan to connect to a primary care provider if no relationship exists. Frequently the immediate follow-up for a behavioral health patient is with a mental health provider, who cannot easily coordinate with primary care if this

information is missing from the CTR.

2. If a patient visits the ER in behavioral health crisis but is not admitted as an inpatient (because, for example, she is referred to a crisis stabilization unit or other outpatient site), the patient's managed care organization (MCO) is not alerted to the ER visit. An inpatient admission requires authorization from the MCO, so the staff at the hospital will contact the utilization management department at the MCO to authorize the admission. The MCO utilization management staff will then pass information about a particular inpatient onto their care coordination staff. But when a patient visits the ER and is *not* admitted, the hospital does not contact the MCO for authorization, and the only contact between the hospital and MCO is much later, when the claim is submitted. By the time the MCO receives the claim, they have missed the opportunity to intervene in the transition from the ER to community-based stabilization and recovery services.

The feasibility study may produce lessons for other primary care-outpatient behavioral health-hospital partnerships, and the State's plans to implement an Admission, Discharge, and Transfer messaging system as part of the Health and Human Services Transformation is a hopeful sign that local experiments and statewide public investment will align to produce real, long-term solutions.

Practice Culture Challenge for Primary Care and Behavioral Health Providers

Health & Medicine's role as convener of the Learning Collaborative allowed us to engage with providers from an objective perspective which enabled behavioral health and primary care providers to articulate their basic philosophical and practical approaches to issues like sharing patient information. While everyone agreed that data exchange was necessary to coordinate care, key practice culture differences emerged.

For example, during a conversation about regulatory reform, a behavioral health provider described a state requirement for clinicians to request consent to share information with a primary care provider for every client, and to record the request in the client's chart. Because it was a mandated activity, the agency leadership requested that clinical staff use a form to ask for consent as soon as possible. Social workers at the agency were unsettled by this, and viewed the imperative to record the request for consent as one more regulatory hoop to jump through that interfered with their ability to engage clients and build trust. Other regulatory burdens cited by the agency were inconsistent criteria for prior authorization of psycho-social-rehabilitation services, duplicative trainings for State- and MCO-required certifications, and double data entry for mental health assessments and electronic health records.

But the consent process raised particular concerns for clinicians. A client initiating services for a behavioral health condition is already in a vulnerable position. A client's primary care provider may represent an authoritative figure, and to demand of the client (as it felt to the clinician) permission to share details and personal information appeared to be an intrusion on the relationship-building necessary in the early stages of treatment. The client and clinician, working together, should be left

more discretion regarding when communication with a primary care provider is necessary and should obtain consent at that time, in the context of a shared, client-directed care plan.

On the other hand, a primary care provider who is also a member of the Learning Collaborative expressed a concern that the “culture of confidentiality” in behavioral health contributes to the failure to deliver timely primary care. Waiting for a reason to contact a behavioral health consumer’s primary care provider likely means waiting too long—until a physical condition manifests itself in a noticeable way—making management and prevention even more challenging.

Furthermore, this primary care member argued that an urge to over-protect mental health and substance use disorder data, while intended to insulate people from the effects of stigma may in fact reinforce the stigma by implying that mental illness is shameful in a way that other health conditions are not. We take for granted that our cardiologist is communicating with our primary care provider, but we cringe at the thought that a mental health specialist would disclose similar clinical information without an urgent justification. The assumptions at work here serve to strengthen and reproduce the stigma, and its negative consequences for patient care, that we agree need to be eliminated.

This disagreement about when and how to communicate with a behavioral health client’s PCP (or to establish a primary care relationship if none exists) represents a basic philosophical difference about privacy, stigma, and power within the healthcare system. On the one hand, behavioral health providers recognize that stigma operates in powerful ways that can hurt consumers (more on this in the next section), which results in people being less willing to pursue treatment that can support recovery. While accommodating stigma by hiding mental illness and substance-use disorder (SUD) information is, in this view, regrettable but necessary in the current moment given the power that medical professionals (and law enforcement) have over people with mental illness and SUD. Health care professionals, the justice system, and the media have, unfortunately, given people with mental illness and SUD many reasons to fear that such power will be abused in the form of discrimination, criminalization, and mistreatment.

On the other hand, we may feel called upon to obey a different principle, one that demands that we do not accommodate current unjust conditions that produce stigma, thereby bringing about change in views and actions that will fundamentally alter those conditions. In this view, to accommodate stigma is to keep us all mired in the current moment’s failure to treat people with mental illness and SUD fairly and equitably. This view regards the harm to patients from sharing “sensitive” information as more imagined than real and, in any case, as the result of rampant, unchallenged stigma, rather than the exchange of information.

Of course anyone, whatever degree of connection they have to mental illness or health care systems, can hold either of these views (or something entirely different). Perhaps primary care providers tend toward the view that sharing more information is better and that withholding only behavioral health information is stigmatizing and counterproductive. Behavioral health providers may tend to be more skeptical that the risks from data exchange are outweighed by the benefits. If this is the case, then we need to work to bridge this philosophical divide along with reducing technological and regulatory

barriers to integration.

Indeed, the Illinois Medicaid program, through Integrated Health Homes and the Behavioral Health Transformation 1115 waiver, will soon demand integrated data exchange on an unprecedented scale. To meet these demands and to make integrated care meaningful for providers and for patients, differences in practice culture toward confidentiality will need to be overcome. One unifying principle, present in both the ideal of the patient-centered primary care medical home and the recovery approach to mental illness and SUD, is that the needs of the patient/consumer's must come first and that providers should support them in participating in care that meets those needs.^{2,3} This points to a way out of the philosophical divide: practice culture cannot be driven by one side winning an abstract argument, but by listening to the people most affected, consumers in the health care delivery system.

The Challenge of Trust for Consumers

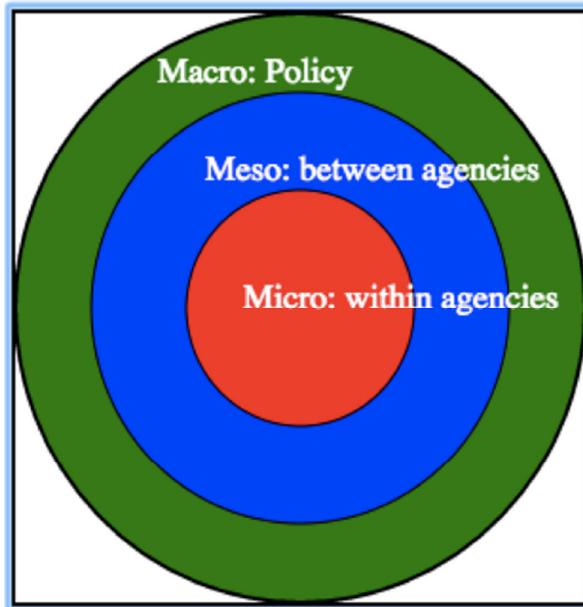
For consumers, data exchange is not a technical or practice-level challenge; instead it represents a personal decision with enormous stakes. For instance, if I share too much information, I may face discrimination and there is evidence for negative bias in both diagnosis and treatment decisions resulting in people with mental illness receiving less and worse care that reflects stigma within the health profession. Research on diagnostic overshadowing highlights the disparities in access to appropriate treatment and in morbidity and mortality.^{4,5} In the Learning Collaborative, we have also discussed the importance of understanding that experiences of discrimination in a healthcare setting can be traumatizing. If a purported healer rejects my reports of physical symptoms and attributes them to a pre-existing mental illness without sufficient assessment, would I not be prudent to withhold trust in the next provider who asks permission to share my mental health diagnosis?

Yet sharing too little information carries risks of adverse drug interactions, delayed diagnosis and intervention for other health conditions, and sub-optimal care from fragmented, duplicative services. Gaps in information exchange lead to failures to access timely primary care, which interfere with prevention and management of chronic physical health conditions. This has major consequences for the quality of life and longevity of people with mental illness.⁶

An overlooked solution to overcoming mistrust and engaging consumers in the decision to share information as part of a shared treatment plan is peer support. Peer support services are an evidence-based model of care that has demonstrated improvement in individuals' relationships with their health care providers (including physical health providers) which ultimately lead to better engagement in both mental health and physical health care.^{7, 8, 9, 10} With the move toward integration of mental and physical health care services, peer support services are increasingly delivered in primary care settings in order to link individuals to needed mental health services more quickly and lessen the stigma of seeking such services. That link can also be leveraged for people who only receive behavioral health services and do not have a primary care provider.

Future Policy Directions

To monitor our progress in the Learning Collaborative, we have adopted a framework to demonstrate the different levels of activity, support, resources, and interactions between organizations represented in the Collaborative:



Micro-level: Support for individual member's quality improvement initiatives; feasibility studies/pilots of interventions within behavioral health or primary care organizations

Meso-level: Peer-to-peer learning and facilitating partnerships; feasibility studies/pilots of interventions that require inter-organization cooperation

Macro-level: Engage policy makers to address barriers to implementing micro- and meso-level changes

LEVEL OF INTEGRATION ACTIVITY FRAMEWORK

The goals we hold ourselves accountable to are that our experiences with micro- and meso-level changes will inform our macro-level policy strategy, and our understanding of macro-level policy changes will inform how we implement micro- and meso-level changes. By instituting this responsiveness between levels of activity, we believe the Learning Collaborative can bridge policy and practice while creating more sustainable, adaptable interventions that support integrated services.

The three perspectives on data exchange described in this paper relate mostly to integration activity on the micro- and meso-levels —consumers and their families, individual practices, and multiple practices building relationships. On the macro policy-level, Illinois needs a plan for integration that gives providers, payers, and consumers the tools they need in practice to coordinate services and integrate data systems. Policy recommendations for integrated data exchange will be included in an upcoming Learning Collaborative policy report.

Conclusion

Integration of behavioral health and primary care services, supported by integrated data exchange, are not ends in themselves. However, integrated services can improve health outcomes for people with chronic and complex conditions. Moreover, outcomes in a recovery framework are driven primarily by the self-determination of the consumer. **While there are technical decisions about platforms and portals, and operational decisions about staffing and consent documentation, the key decisions should be the consumers’.** This includes the decision to disclose a mental illness or substance use issue and the ongoing decision-making inherent in managing their treatment, including sharing data with their different providers. The Learning Collaborative has always emphasized listening as way of learning.-- listening to each others’ experiences and expertise as providers, payers, and especially people with lived experience of disclosed mental illness and substance use disorders as an intentional practice to become and remain open to changing how we think and act in health care settings and in communities. At the Center for Long-Term Care Reform, we believe that *listening* to consumers while supporting recovery--rooted in self-determination--must be a first step toward actually shifting power and control, “out of the hands of those who give care and into the hands of those who receive it.”¹¹

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