

[Introductions]

Our group, as this group is, was a dizzying array of practitioners, policy makers, legislators, and thought leaders with both broad and deep understanding of the perils and possibilities of the healthcare system as it exists today and as it might be tomorrow.

We spent time identifying problems and pinpointing solutions while trying to avoid the pitfalls of being so specific as to be unworkable on the large scale and so broad as to be unworkable on the small scale. At the end you can tell us how we've done.

Improving healthcare for persons with disabilities for persons with disabilities involves envisioning and enacting improvements in the following areas:

- Instrumentation
- Interoperability
- Intelligence

In all the healthcare and health IT recommendations that follow, our assumption is that we're talking about people with disabilities as consumers, patients, practitioners, parents, administrators, stakeholders, across all health systems from billing to clinical care delivery systems. (i.e., accessibility should be designed-in to all aspects of the high-priority areas we have identified.)

Problems:

Technology: Instrumentation and Interoperability and Intelligence

Healthcare should appropriately leverage technology to provide effective, efficient, error-free, timely, honest, and satisfying information transfer within and across institutions and between stakeholders.

Selected examples of problems:

1. Patient-centric longitudinal medical records and care data are not standardized in a manner that can be shared across all aspects of clinical care, public health policy, and practice.
 - e.g., Public Health sectors and clinical care sectors do not interface closely enough to support community monitoring, comparative effectiveness decision making and enable policy makers, patients and/or caregivers to monitor and serve local, regional, and national communities in near-real time.
2. Privacy, care, and public health laws are out of step at the state and federal level with emerging information sharing possibilities.

- Information vital to individual and national interests is housed in silos owned by corporations, insurers, hospitals, and other organizations.
3. Human factors (usability, accessibility) are completely unacceptable across systems. Healthcare technology systems are not usable, effective, efficient, or satisfying to use by the persons intended to use them. Further, they do not effectively capitalize on digital communication and social networking resources in a manner that safeguards individual and public interests

Solutions:

- automation should reduce/eliminate manual data entry wherever feasible
- automation should enhance usability by users

Patients and Caregivers: Essential to the Process :)

Interfacing with healthcare processes and policies is a be a tiresome, confusing, and painful process for patients and caregivers

Examples

- 4. Individuals and caregivers do not have equal access to medical records that support analysis and long-term decision-making
- 5. Consumers are not educated and empowered to look after their own well-being as participants in life-long health strategies
- 6. Consumers are encouraged to take the reins of their healthcare only in times of chronic illness or situational crisis
- 7. Emergent technologies do not yet empower individuals to monitor their health in a way that can be communicated back into clinical decision-making systems.

Solutions:

- Incentivize positive behaviors
- Education through multimedia and person-appropriate learning styles
- Empower patients and caregivers to foster decision making
- Involve and respect individual choices
- Tie individual health to communities of care
- Support caregivers as part of individual health
- Use technology to provide intrinsic safety
- Ensure privacy while leveraging patient-elected data sharing

Vision:

To address such varied issues across so many stakeholders requires significant communication. We identified these guidelines for next steps:

8. Government should have a clearly defined and guiding role as a partner in healthcare in America
9. Inefficiencies and expenses associated with the current system can be curtailed.
 - 30%-40% of healthcare costs are associated with errors and inefficiencies in the current systems.
 - 10% of the healthcare-receiving population accounts for 63% of the costs associated with healthcare nationwide. Earlier interventions with at-risk and chronic care populations may result in savings that could be allocated back into healthcare enhancements.
10. Models of effective healthcare in the US exist and should be leveraged, e.g, the VA's collaborative care model works with patients and reaches beyond institutional borders to incorporate home care when appropriate. (Embodying the Medical Home model)

Solutions:

- Successful systems will reward outcomes, not procedures.
- Incentives should be aligned such that stakeholders support the public interest.
- Healthcare does not provide clear and supported roles for caregivers.
- Healthcare does not reflect the truism that patients are part of communities both large and small
- Emerging solutions are being driven by technology and/or politics rather than a user-centric assessment of successes and failures of the current system.