A Report to the Governor and the Chairmen of the House Appropriations and Senate Finance Committees of Virginia

A PLAN TO IMPROVE DATA GOVERNANCE STRUCTURE IN HEALTH AND HUMAN RESOURCES AGENCIES IN THE COMMONWEALTH OF VIRGINIA

William A. Hazel, Jr., M.D.
Secretary of Health and Human Resources

December 2016

Preface

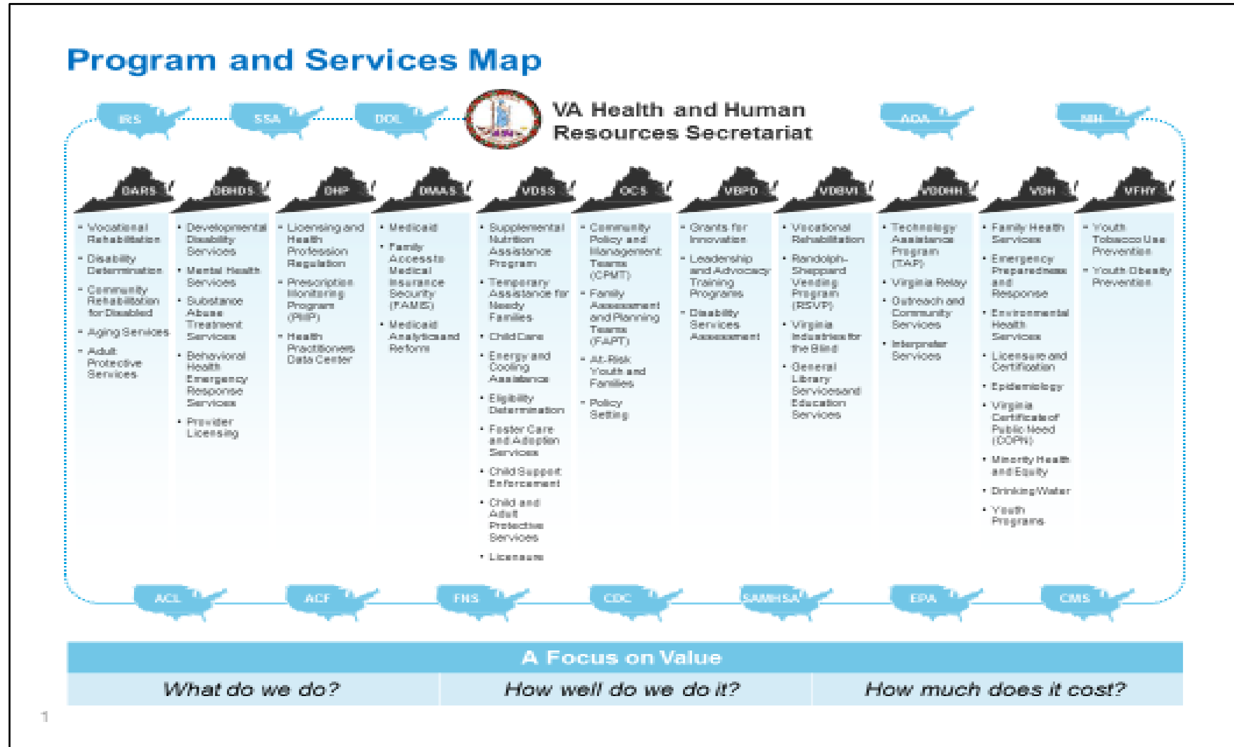
Item 284 #2c of the 2016 Budget Amendment requires:

"B. The Secretary shall develop a plan to address the data governance structure across all agencies in the Health and Human Resources Secretariat in order to streamline business processes, increase operational efficiency and effectiveness, and minimize duplication and overlap of current and future systems development. The plan shall consider how agencies can participate in such a structure while adhering to privacy provisions set forth in state and federal law and regulations. The Secretary shall report on the plan, including challenges impacting the plan, to the Governor and the Chairmen of the House Appropriations and Senate Finance Committees by October 15, 2016."

This report is in response to this mandate.

Introduction

The Secretary of Health and Human Resources (HHR) oversees 11 state agencies (listed below) that provide care, services and support for individuals with disabilities, the aging community, low-income working families, children and caregivers.



HHR in Virginia has embarked on a bold mission to bring about a true systems transformation that will empower the individuals we serve and support to be healthy and productive members of society. The "Road to Self-Sufficiency" (http://www.dss.virginia.gov/geninfo/reports/financial_assistance/sufficiency.cgi) requires that our programs be aligned, efficient, and effective in providing services and supports. For individuals of all ages with disabilities, personal choice and easier access to needed long-term supports that are integrated, individualized and simple to use are a must.

Strategic plans developed by leaders in HHR acknowledge that the best approach to addressing these needs is to transition from a program-centric to a client-centric service model. Achievement of this goal requires an IT platform that both supports the provision of services with the right information in the right setting at the right time and also allows for thorough oversight and evaluation of the effectiveness of services and programs.

As practices and technologies have advanced, the delivery of high-quality health and human services has come to require teams of providers—including primary care physicians, specialists, nurses, technicians, behavioral health workers, social service workers, and other clinicians. Each member of the team tends to have specific, limited interactions with the client and, depending on the team member's area of expertise,

a somewhat different perspective of the customer and how to support them. In effect, the health care team's view of the customer becomes fragmented into disconnected facts and clusters of symptoms and solutions.

The solution to this fragmentation lies in applying the principles of Collective Impact. A robust and integrated capacity to employ data is essential to both achieving and recognizing success.

The Five Conditions of Collective Impact Success

Collective Impact is more rigorous and specific than collaboration among organizations. There are five conditions that lead to meaningful results from Collective Impact:

1. *Common Agenda*: All participants have a **shared vision for change** including a common understanding of the problem and a joint approach to solving it through agreed upon actions
2. *Shared Measurement*: **Collecting data and measuring results consistently** across all participants ensures efforts remain aligned and participants hold each other accountable
3. *Mutually Reinforcing Activities*: Participant activities must be **differentiated while still being coordinated** through a mutually reinforcing plan of action
4. *Continuous Communication*: **Consistent and open communication** is needed across the many players to build trust, assure mutual objectives, and appreciate common motivation
5. *Backbone Organization*: Creating and managing collective impact requires a separate organization(s) with staff and a specific set of skills to **serve as the backbone for the entire initiative and to coordinate participating organizations and agencies**

Progress to Date

Significant progress in this transition has been made over the last five years.

1) The process of applying for public assistance has been modernized and migrated to a (new) single case management system (VaCMS).
2) Citizens can now apply for public assistance on-line or through a call center, have their identity authenticated, and manage their information, or receive status updates.
3) Citizens can follow a Self-Direct application process.
4) Large volumes of paper files have now been converted to electronic files. Local Department of Social Services (LDSS) have converted most of their benefit program case files to an electronic record system which enables immediate eligibility determination using an automated rules engine.
5) DARS No Wrong Door (NWD) initiative allows individual records on the provision of services to elderly and disabled Virginians to be shared among Area Agencies for Aging and their community based partners. This includes LDSS and some Community Service Boards (CSBs). By late 2018, NWD will include all LDSS for Adult Services programs.
6) Data Analytics Units have been established in DMAS, DSS, DBHDS, DARS, VDH, and CSA.

7) HHR has created an "Enhanced Memorandum of Understanding" (eMOU) to facilitate multi-party sharing of data with all required privacy and security restrictions.

Key elements of the transition to a client-centric service model require additional innovations to governance and data management that have not yet been achieved.

There is a large and growing body of research showing that health outcomes are significantly influenced by a number of social and environmental factors which are referred to as the "Social Determinants of Health". Examples of such factors include such obvious conditions as poverty, poor education, lack of stable housing, family violence, and/or substance abuse.

Health and Human Resources program challenges and costs in turn are driven in large part by a relatively small number of individuals with multiple physical and behavioral health conditions which are often exacerbated by extreme poverty, trauma, mental and physical impairments, and substance use disorders. These high needs clients often have significant social support needs for economic, housing, nutritional, educational, and/or employment support.

Example of the benefit of data sharing

VDSS and IBM recently examined enrollment in 5 different programs (Medicaid, SNAP, TANF, Child Protective Services, and Family Services) under the purview of VDSS in an effort to determine how many individuals were engaged in more than one of these programs. A total of 2.66 million people were enrolled or listed in these programs that year. After matching and removing duplicates the results indicate that 35 percent of enrollees (929,260) were in two or more of these programs. Ten percent show up in three or more of these programs.

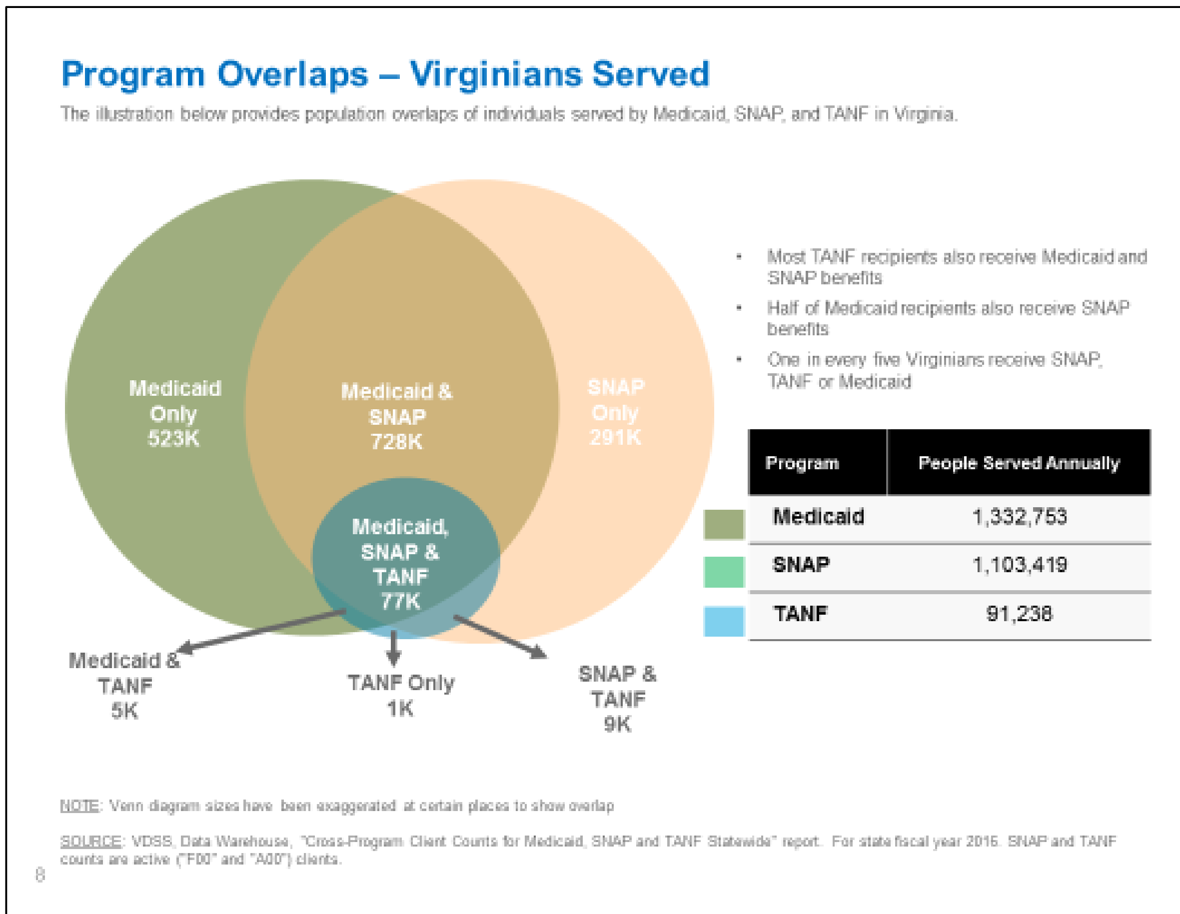
Member Overlap Analysis

Source	No. of Members	# of Members with Overlaps	% of Members with Overlaps	Count in CPS	% in CPS	Count in FC	% in FC	Count in FS	% in FS	Count in MA	% in MA	Count in TANF	% in TANF
CPS	47,403	31,256	66	47,403	100	503	1	26,759	56	29,893	63	7,291	15
FC	2,553	2,366	93	503	20	2,553	100	979	38	2,288	90	325	13
FS	1,211,982	853,134	70	26,759	2	979	0	1,211,982	100	844,697	70	111,711	9
MA	1,283,516	855,060	67	29,893	2	2,288	0	844,697	66	1,283,516	100	109,435	9
TANF	117,293	116,703	99	7,291	6	325	0	111,711	95	109,435	93	117,293	100

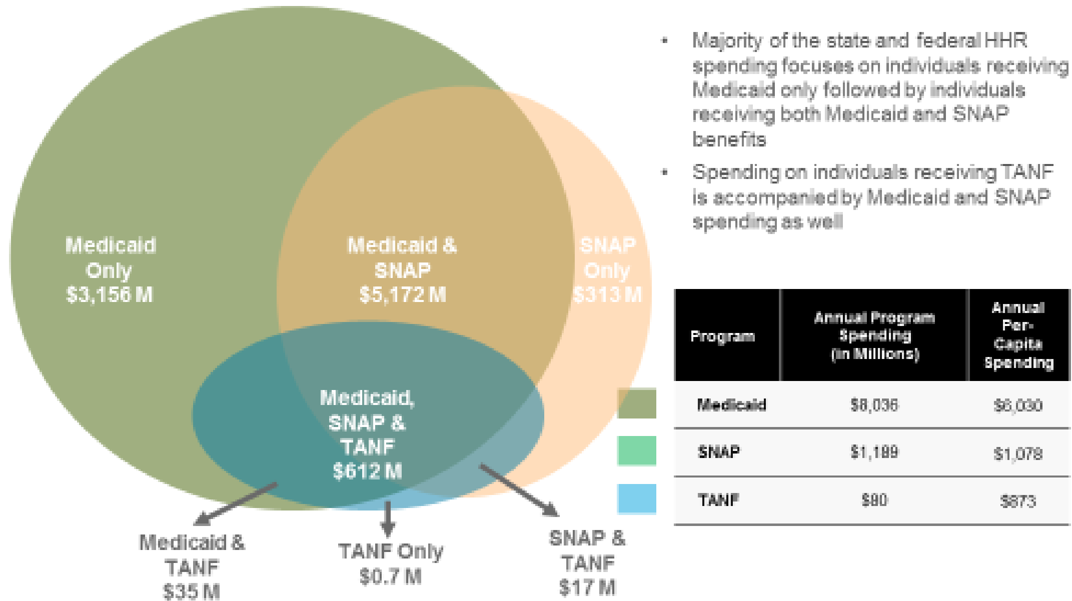
- Total Members (including duplicates) = 2,662,747
- Total Members with Overlaps = (1,858,519 / 2) = 929,260

Clearly these programs should not be operating independently of each other if the benefit of the intervention is to be maximized.

Additionally, case workers typically spend between 2.0 and 2.5 hours on average to complete an eligibility review for SNAP, TANF or Medicaid cases. For clients enrolled in all three programs a case worker may conduct three separate reviews during the year, one for each program. Since most of the information needed to evaluate eligibility for these programs is the same, it was estimated that synchronizing the reviews could save up to $23 million per year.



Program	People Served Annually
Medicaid	1,332,753
SNAP	1,103,419
TANF	91,238



Program	Annual Program Spending (in Millions)	Annual Per-Capita Spending
Medicaid	$8,036	$6,030
SNAP	$1,189	$1,078
TANF	$80	$873

If HHR agencies were able to match individuals across these programs, additional benefits could be anticipated. These benefits include improved program administration through potential reductions in fraud and abuse, reduction in duplicate filings, reduction in payment errors, fewer phones calls between staff and clients and a better understanding of total benefits to individuals and households. Additionally, the ability to identify which individuals are more likely to require longer term or more intensive services would permit more effective case management and would likely improve outcomes.

Legal considerations for appropriate use of data

Neither the United States nor the Commonwealth has a comprehensive data sharing law. Rather, the evolution of data protection and privacy laws has led to an extensive array of narrowly tailored, state and federal laws, regulations, rules and policies ('formal constraints') that govern the collection, maintenance, use, and dissemination of data. The vast majority of these formal constraints were designed to address a particular issue and relate to a specific industry or subject matter.

The primary deterrent to the use of administrative data in Virginia is the Virginia Government Data Collection and Dissemination Practices Act (GDCDPA) of 1976 which limits the use of data to the purpose for which it was collected. Purpose was undefined in this statute.

The Health Insurance Portability and Accountability Act of 1997 (HIPAA) defined permitted disclosures of protected health information when certain safeguards are in place as:

> A covered entity is permitted, but not required, to use and disclose protected health information, without an individual's authorization, for the following purposes or situations: (1) To the Individual (unless required for access or accounting of disclosures); (2) Treatment, Payment, and Health Care Operations; (3) Opportunity to Agree or Object; (4) Incident to an otherwise permitted use and disclosure; (5) Public Interest and Benefit Activities; (6) Limited Data Set for the purposes of research, public health or health care operations. Covered entities may rely on professional ethics and best judgments in deciding which of these permissive uses and disclosures to make.

De-identified data is not protected health information and is not covered by this privacy rule.

HIPAA defined Health Care Operations to be:

> any of the following activities: (a) quality assessment and improvement activities, including case management and care coordination; (b) competency assurance activities, including provider or health plan performance evaluation, credentialing, and accreditation; (c) conducting or arranging for medical reviews, audits, or legal services, including fraud and abuse detection and compliance programs; (d) specified insurance functions, such as underwriting, risk rating, and reinsuring risk; (e) business planning, development, management, and administration; and (f) business management and general administrative activities of the entity, including but not limited to: de-identifying protected health information, creating a limited data set, and certain fundraising for the benefit of the covered entity.

There are additional federal laws and rules limiting access to psychotherapy notes (CFR 45 164.502). The Code of Virginia prohibits disclosure of laboratory results for HIV testing although clinical notes and diagnoses can be shared. Neither precludes the use of administrative data.

The Family Educational Rights and Privacy Act (FERPA) places restrictions on the use of educational data. Because Virginia has a state-supervised and locally-administered human services structure, an unintended consequence is that VDSS is not deemed to have custody of children who are in the social services system for the purpose of accessing educational data. Without knowing such things as school attendance and performance, it is more difficult to assess the benefit of state support to these children.

Executive Directive 7

Executive Directive 7 (ED7), subtitled *Leveraging the Use of Shared Data and Analytics* stated that management and integration of data across a secretariat is key to eliminating redundancy, streamlining services, simplifying customer interactions with the state and its partners, and supporting citizen's needs. The goals for data governance and management in HHR align with Governor McAuliffe's goals set out in Executive Directive 7:

- Enhancing government transparency
- Streamlining business processes
- Increasing operational efficiency and effectiveness
- Minimizing duplication and overlap of current and future systems development

Information collected in preparation for the report required by ED7 found that HHR agencies own 517 data sets. Currently only 80 of these data sets are shared with other agencies, more than in any other Secretariat.

Best practices for data sharing include:

- Engaging legal counsel to review and document compliance requirements;
- Enforcing compliance through audits on source and downstream data systems;
- Establishing compliant requirements for physical and logical access controls;
- Providing regular training and technical support relating to compliance;
- Adopting standardized templates or trust frameworks for data sharing agreements;
- Implementing restricted use agreements to control use of shared data;
- Requiring compliant electronic authentication for data access [§ 59.1-550 et seq.]; and
- Designing data sharing interfaces to conform to external data exchange standards.

Best Practices for data analysis include:

- Insuring data quality, integrity, values and constraints;
- Implementing established methodologies for analytics;
- Adopting methods, formats, and data visualization techniques aligned with requirements;
- Aligning data analytics requirements with data governance models; and
- Following data analytics methods, standards, and established techniques.

Data Governance Models in Virginia

One example of a strong governance model for de-identified data currently in place within state government is the Virginia Longitudinal Data System (VLDS), which is hosted by the State Council for Higher Education in Virginia (SCHEV). VLDS features participation by multiple state agencies and has a solid, trust-based governance model with oversight by a central coordinating committee. Several HHR agencies participate in this system, including VDSS, DHP, and DARS. CSA is in the process of "on-boarding" to VLDS. DMAS will participate upon implementation of a new data warehouse. Modest funding ($20,000) is required for on-boarding and on-going participation. A major limitation at present is that VDH does not yet participate. Funding has been cited as the reason.

Recommendations

The needs and goals described by health and human resources agencies require a more streamlined ability to both protect and secure data and to share it when necessary and appropriate for good public policy or to improve the services rendered to an individual or family. Privacy and security are compatible with programmatic improvement. When it is already acceptable and legal to share data, the processes by which this can be done must be simplified to ensure that information can be obtained in a timely fashion.

The following actions and initiatives have been identified to address data governance, privacy, and security within the HHR Secretariat:

1. The General Assembly should define HHR as a single program for the purpose of governing and managing its data; this change could be achieved through a budget amendment. Privacy and security policies should be consistent with HIPAA and HHR agencies should become HIPAA compliant.

2. The General Assembly should clarify that that the purpose for which data is collected includes uses defined under HIPAA. These include determining eligibility, providing services, ensuring accurate payment, identifying and investigating fraud and abuse, policy analysis, program evaluation, performance monitoring, and outcome measurement are legitimate uses of identifiable data, and that identifying where clientele overlap from one program to another is necessary in order to achieve program efficiencies.

3. The General Assembly should encourage updating of the enhanced memorandum of agreement (eMOU) that has been developed by the Office of the Secretary of Health and Human Resources and this memorandum should become the basis for multi-party data sharing between HHR and other state agencies outside of HHR. Revisions and enhancements to the eMOU are needed to clarify purpose and constraints, definition and description of metadata, data records to be provided, and the method that will be used to exchange data.

4. The General Assembly should encourage development of model memoranda of understanding to facilitate the necessary bi-directional exchange of information with localities and between localities, as localities require state data and vice versa. Citizens are mobile and communication and coordination are necessary between localities for services that are provided today.

5. The General Assembly should leverage investments in technology where possible, including enterprise level analytics as a service (modeled after programs in South Carolina and Washington State). This change would provide savings to the state through economies of scale, and Virginia may realize additional benefits by utilizing 90/10 match funding from federal agencies to pay for technology investments.

6. The General Assembly should encourage the Secretary of HHR to establish a cross-agency data governance structure and process for the Secretariat. This would require staff augmentation with specific expertise and responsibility in:

    a) Development and coordination of data security and management policies;
    b) Development and use of shared standards and common technology architecture for identity matching, finance, and procurement;
    c) Development of data dictionaries, metadata and other information about the data within each agency, including any restrictions that may exist on the use and sharing of specific data elements;
    d) Improvement of data quality;
    e) Integration of data across different source systems;
    f) Development and adoption of data classification standards across agencies;
    g) Assist agencies in developing useful open data platforms for information that should be in the public domain: and
    h) Encourage a culture or data stewardship and collective ownership for the public benefit.

7. The General Assembly should consider funding on-boarding and maintenance of the Virginia Longitudinal Data System (VLDS) to enhance broad-based program evaluation of program effectiveness.

8. The General Assembly should establish a Public-Private Data Collaborative composed of representatives from HHR agencies, local agencies, research universities, and private entities to identify data needs related to health and human resources and best practices for data governance within the Commonwealth.