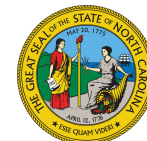# Developing enterprise level infrastructure and governance for data sharing

**Jessie Tenenbaum, PhD**
**NC Health & Human Services**

**Amy Hawn Nelson, PhD**
**Actionable Intelligence for Social Policy, UPenn**

**August 2020**

**AISP**
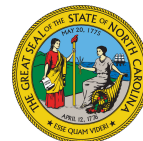
NC DEPARTMENT OF
**HEALTH AND**
**HUMAN SERVICES**
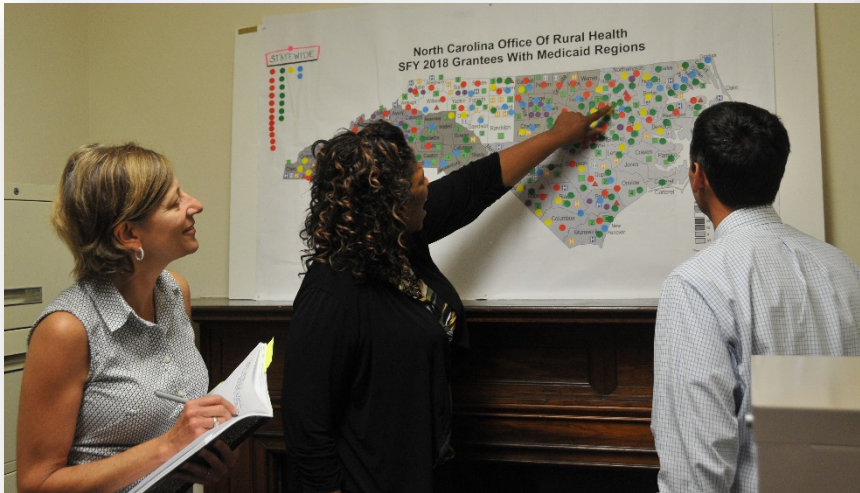
# Department Overview

- Led by Secretary Mandy K. Cohen, MD

- Second largest state agency in NC

- Employs over 16,000 people

- Receive the second-largest appropriation from the General Assembly

- Budget of $20.5 billion

  90% of expenditures go toward aid and public assistance for beneficiaries of programs such as Medicaid and food stamps



NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**
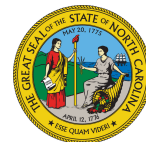
# Department Overview

- 30 divisions and offices in four broad service areas:
  - Health
  - Human services
  - Administrative
  - Support functions





NC DEPARTMENT OF
**HEALTH AND HUMAN SERVICES**

# Key Services

- With over 260 services, DHHS touches the lives of virtually every North Carolinian from birth to through the end of life. This includes:
  - Medicaid
  - Foster care
  - Prenatal programs
  - Child development/early education programs
  - Food and nutrition benefits programs
  - Regulation of healthcare facilities





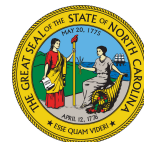NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**

# We focus on "buying health" across our Department

## Three Priorities:

Medicaid Transformation

Early Childhood

Combatting the Opioid Crisis
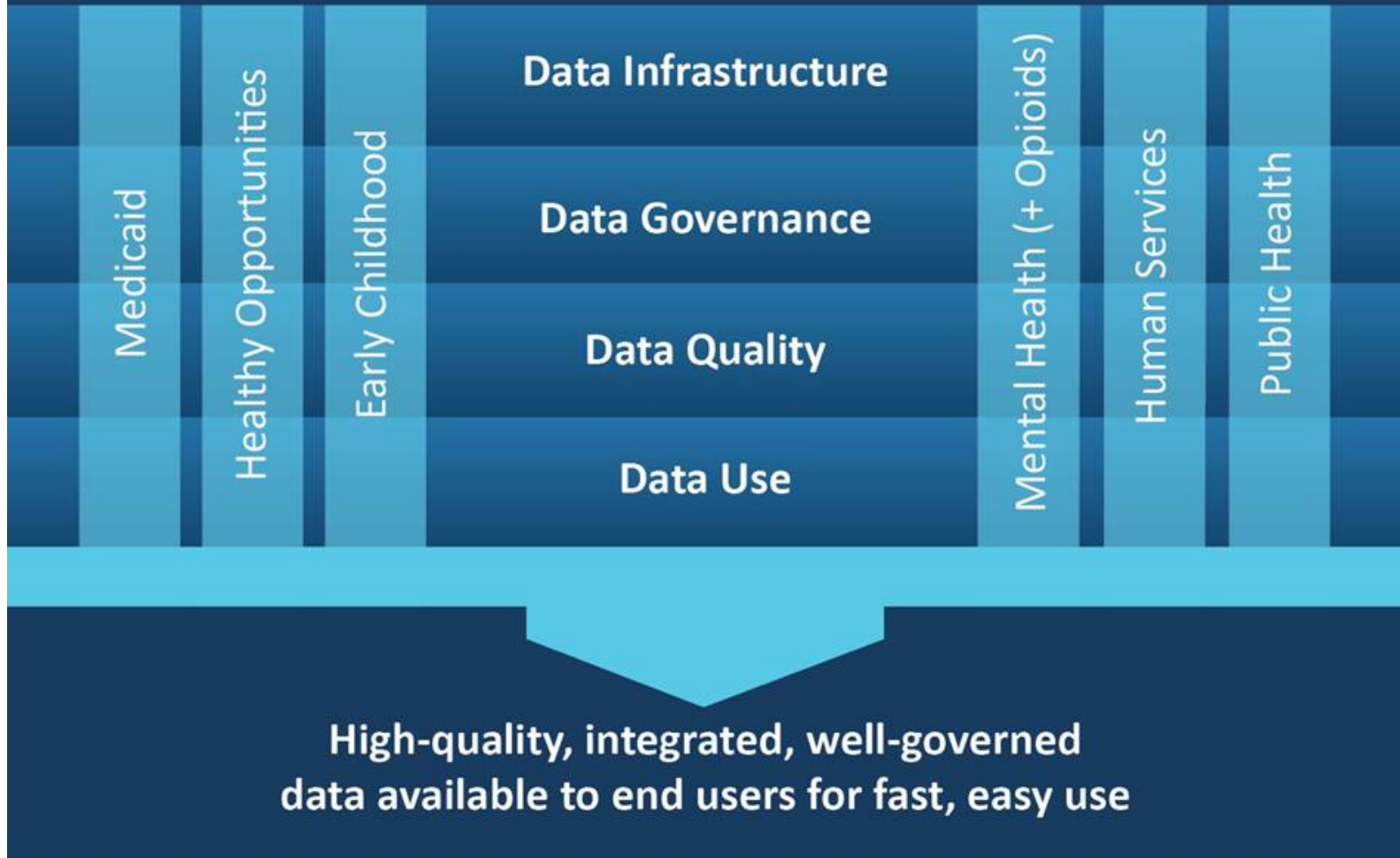
NC DEPARTMENT OF
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# Moving from Descriptive to Predictive
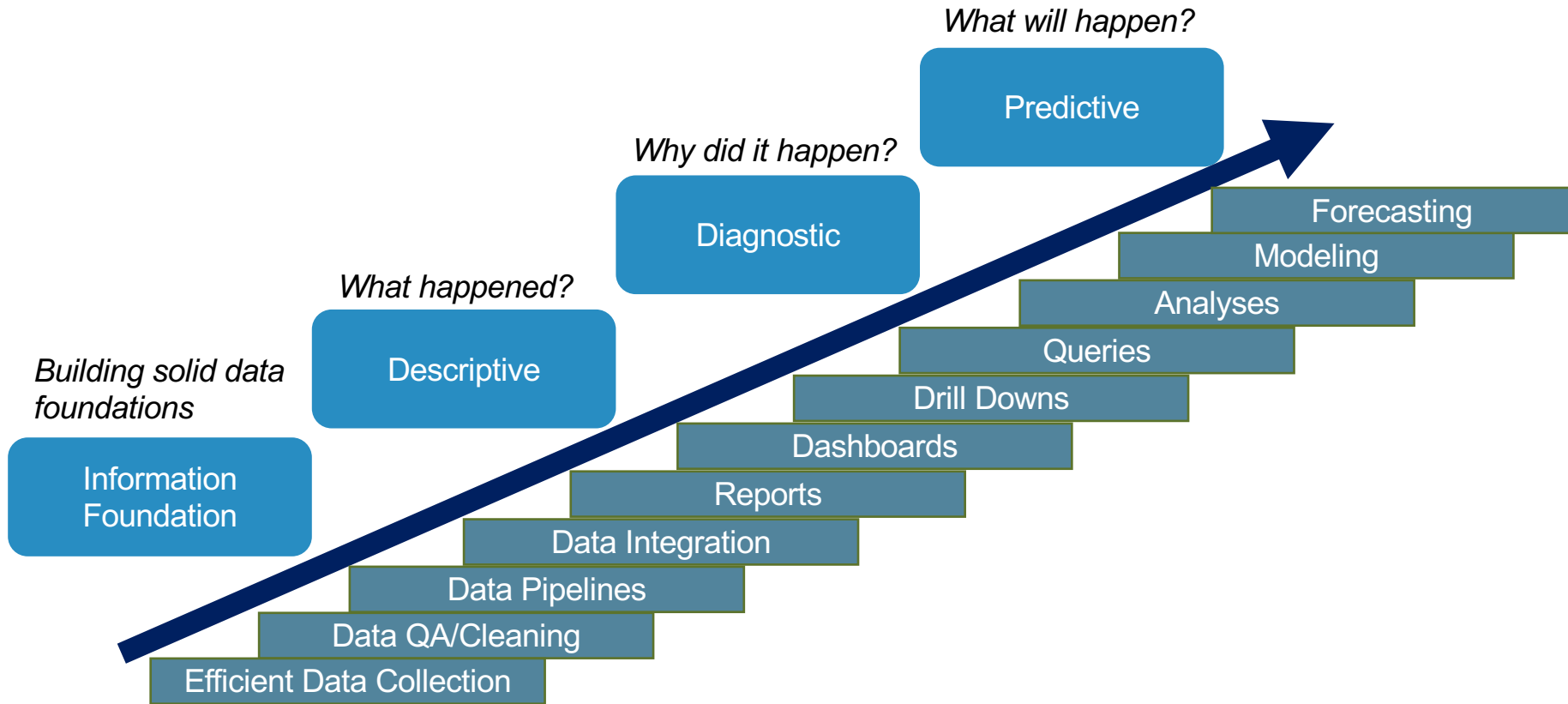
# Why focus on standardizing process for data access and use?

- **Benefit serving NC residents:** Data integration supports holistic insights that can result in better service and outcomes at a lower cost across the enterprise, and ultimately place DHHS in a better position to "buy health."

- **Mitigating risks:** DHHS data has either been open or padlocked. Both approaches have intended and unintended consequences that lead to risks (either missing insights or risks of privacy redisclosure).

- **Supporting staff:** Data access is a pain point, as staff want to use data in alignment with their roles and responsibilities, not spend their time begging and pleading for data.

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# Process

| | | | | |
|---|---|---|---|---|
| NC DHHS created Data Office, hired Jessie Tenenbaum as CDO<br><br>AISP brought on to provide Technical Assistance | Staffing the Data Office<br><br>Developing Data Strategy<br><br>Data Collection for Landscape Overview | Building support for data strategy<br><br>Data Collection, Presenting Findings, Refining Strategy | Building support for strategy<br><br>Then, COVID! All work shifted.<br><br>Designing processes and procedures | Iterations of process & documents. Review by Legal, Privacy Officers, and Divisions<br><br>Refine, implement, and build |
| **Summer 2019** | **Fall 2019** | **Winter 2019/2020** | **Spring/ Summer 2020** | **Fall 2020** |

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# AISP'S Role

**We help state and local governments collaborate and responsibly use data to improve lives**

| We are: | We are not: |
|---|---|
| Data evangelists | Data holders or intermediaries |
| Connectors, community builders, thought partners, cheerleaders, and data sharing therapists | A vendor or vendor recommender |
| Focused on ethical data use for policy change | Focused on academic research |

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# North Carolina Department of Health and Human Services
# Data Landscape Overview

**January 2020**

Goals of this document:
- Describe perspectives of DHHS staff and contractors in regards to data infrastructure, data governance, data quality, and data use across the DHHS enterprise.
- Identify strengths, weaknesses, opportunities, and threats in regards to infrastructure, governance, quality, and data use to support data strategy development by the DHHS Data Team.

Data Collection Activities:
This Data Landscape Overview has been developed through engagement with NC Department of Health and Human Services staff and contractors via in-person meetings, document review, a survey of data sharing agreements (led by division director and legal counsel), weekly calls with DHHS Data Team, and structured interviews, both in-person and by phone, with 44 individuals from September 2019 to January 2020.

Analytic Approach:
Notes from structured interviews were reviewed multiple times and thematically coded.  A theme was not included in this overview document unless mentioned 3+ times by respondents and/or corroborated by another data source (document, meeting, email, etc.).

Amy Hawn Nelson, PhD
Actionable Intelligence for Social Policy, University of Pennsylvania
ahnelson@upenn.edu, 704.616.0796
Funded by NC Department of Health and Human Services

# Recommended Steps in Alignment with the Data Strategy Roadmap

Data Infrastructure:
- Continue the course towards enterprise data management procurement.
- Set up a secure and central environment that can function as a linking hub for cross-division data integration.
- Develop a routine approach to secure data transfer.

Data Governance:
- Develop clear access and use procedures based on data, type of request and credentials of requestor (ex. audit group has broad access and view only, DPH analysts receive regular aggregate reports with standardized requests, etc.).
- Develop templated foundational legal agreements for use across the agency, with division specific Data Sharing Agreements that describe technical parameters across the data life cycle.
- Begin development of a data access and use legislative agenda, starting with existing federal regulations and state rules around administrative data access and use.
- Develop an open data policy that clearly identifies data that can be shared with public audience.

Data Quality:
- Continue data documentation efforts, drawing upon depth of content expertise within divisions.
- Continue to build culture of continuous improvement to support data quality.

Data Use:
- Continue quick win analyses.
- Continue capacity building through user groups and cross agency collaborations, such as the Early Childhood Action Plan and the Opioid Taskforce.

# Beyond COVID-19: NC DHHS Data Sharing Guidebook

Develop an "outlasting" Data Sharing Guidebook, to include:

- Department priorities for data access & use
- Overview of department roles that support data sharing and use to better understand purposes and best practices
- NCDHHS high value data asset inventory
- NCDHHS data request process for NCDHHS employees & process for external partners
- Overview of legal framework for internal and external sharing and integration, including current federal and state statute and rules
- General data classification guidance (open, restricted, unavailable)

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| OPEN DATA | RESTRICTED DATA | UNAVAILABLE DATA |
|---|---|---|
| Data that can be shared openly, either at the aggregate or individual level, based on state and federal law. These data often exist in open data portals. | Data that can be shared, but only under specific circumstances with appropriate safeguards in place. | Data that cannot or should not be shared, either because of state or federal law, lack of digital format (paper copies only), or data quality or other concerns. |

## Data Classification Matrix

| | |
|---|---|
| Data can be shared with agreement and approval through governance | Open data; can be shared without an agreement |
| Not shareable | Technology and/or data structure limits ability to share data |

# Questions?

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**AISP**