Finding a Way Forward: Models of Successful Cross-Sector Data Integration

Deja Kemp, JD Director of Legal Policy

Actionable Intelligence for Social Policy (AISP)



Getting Started: Menti Code: 7439 9200





Join at menti.com use code 7439 9200

Mentimeter

What reasons have you heard for why data cannot be shared?

Waiting for responses ...

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3



Turn & Talk, 2 minutes

Find a partner and discuss the prompt. What reasons have you given a client for why they can't share data and what was their reaction?



Finding A Way Forward



While there are times where there will be clear "Nos", often times there are:

"Yes AND"
"Yes BUT"
"Maybe"
"No, But"



This resource will help you to imagine other possibilities beyond "No"

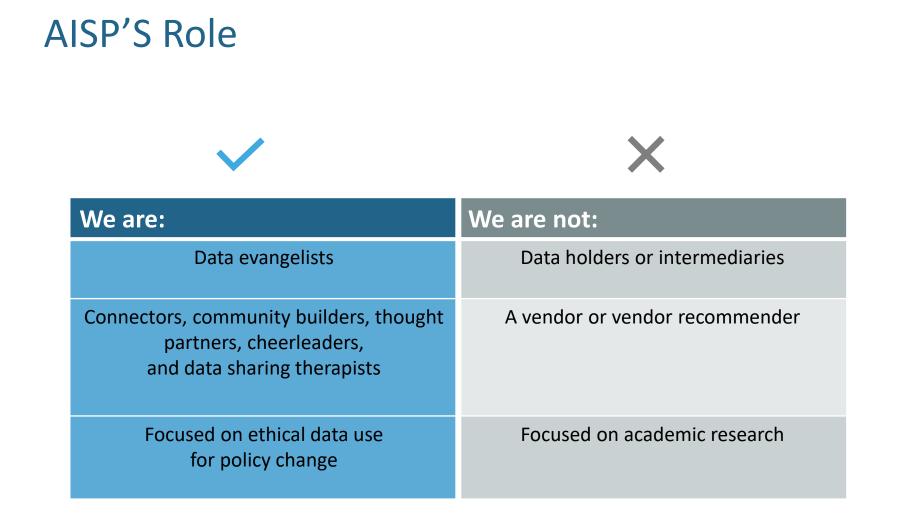


Helping state and local governments collaborate and responsibly use data to improve lives.

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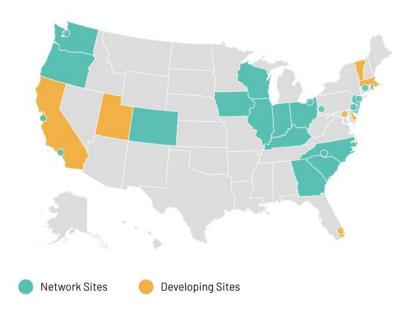


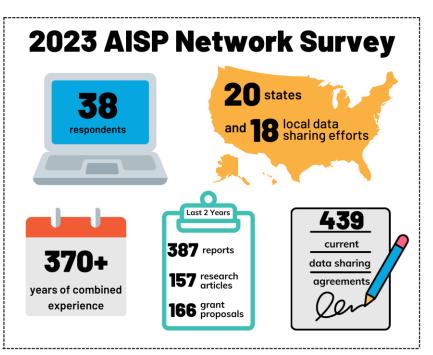




Our Network

Network of 36 state and local integrated data systems (also known as data hubs, data collaboratives, etc.) who come together regularly to share best practices







What we do

Peer Network

Guidance & Standards

Training & Consulting

Advocacy & Communications

Actionable Research



Our approach

Data sharing is as relational as it is technical.

We don't just need to integrate data; we need to integrate people.



When we talk about IDS, what do we mean?

- We're talking about people, not tech solutions
- Efforts that link administrative data across domains/agencies
- Efforts that curate data that are relevant and high quality
- Efforts that serve as a public utility (not research for research's sake)
- Efforts that have defined governance structures (data only used for approved uses)





LEGAL PUBLICATIONS





Quality Framework for IDS

Governance	Data governance is the people, policies, and procedures that support how data are used and protected.	
Legal	Whether data can be shared legally depends on why you want to share, what type of information will be shared, who you want to share with, and how you will share the data. Legal agreements should reflect the purpose for sharing, document the legal authority to serve that purpose, and ensure that data sharing complies with all federal and state statutes.	
Technical	Technical components are created to support analytics and insights that can help further improvements in policies, practice, and outcomes.Data sharing capacity refers to the staff, relationships, and resources that enable an effort to operate governance, establish legal authority, build technical infrastructure, and above all else, demonstrate impact.	
Capacity		
Impact	All components of quality—governance, legal agreements, technical tools, and staff capacity—exist to drive impact.	

See more at aisp.upenn.edu









Is this legal? Authority and Access

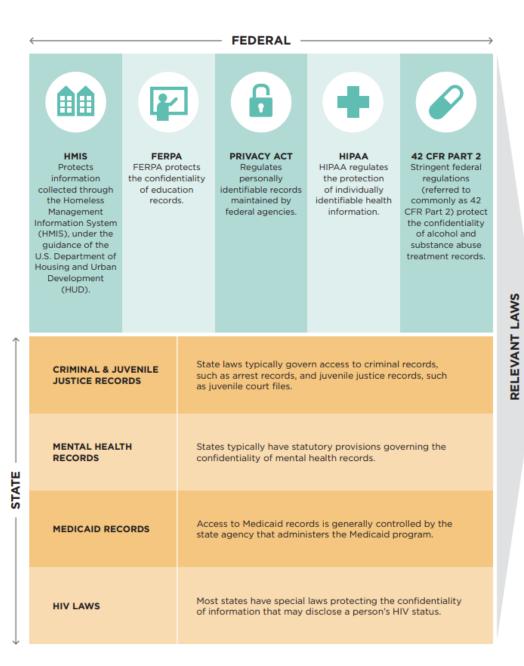


Open Data	Restricted Data	Unavailable Data
Data that can be shared openly, either at the aggregate or individual level, based on state and federal law.	Data that can be shared, but only under specific circumstances with appropriate safeguards in place.	Data that cannot or should not be shared, because of legal restriction or another reason (e.g., data quality concerns).

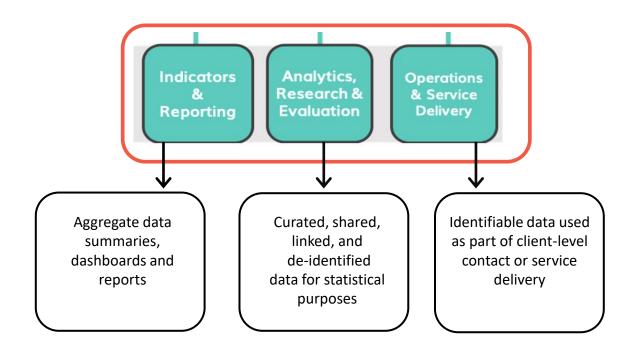


State & Federal Laws





Start at the beginning: what is your core purpose(s) for data sharing?





Purpose has important implications

Core Purposes and Approaches for Data Sharing and Integration

Purpose for data sharing and integration	Indicators and Reporting	Analytics, Research, and Evaluation	Operations and Service Delivery
Approach	Data can be summarized and reported at the aggregate	Data must be curated, shared, linked, and then de-identified for statistical purposes	Data must be identifiable and may include case notes to support client- level services
Legal Framework	Data may be publicly available already or may require a simple Data Use Agreement to receive in de- identified format	Data access will generally require multiple agreements, including a Memorandum of Understanding and Data Use License/Agreement to clearly outline permissible access and use	Data access may require client consent and non- disclosure agreements. Data agreements must outline parameters for role-based, credentialed access
Data Frequency	Data may be updated based on reporting cycles, quarterly or annually	Archive of select data may be updated periodically depending on availability and analytic requirements	Daily or real-time updates of entire client records may be required
Privacy and Security	A lack of identifiers or small cell sizes means minimal risk of redisclosure, although demographic information, dates of service, diagnoses etc., mean that data are potentially reidentifiable and must be covered by a Data Use Agreement (except for statistically approved aggregate measures)	Minimal access to identifiable data and small group of approved users means that security requirements are essential but basic	Many users and identifiable data mean that complex permissions and audit trail will be necessary
Cost	Minimal	Moderate	Significant
Difficulty getting started?	Can be difficult, depending on the familiarity of partners	Difficult; labor- and time- intensive	Significant investment of time, labor, and financial resources
Governance	Minimal	Clear parameters around access and use are required, shared processes involving all agencies	



Practice: Defining Access and Use to Determine Legality

Practice: Defining Access and Use to Determine Legality

Ready to get started? Use the following prompts and examples as a guide to clearly define your data access and use, which then allows you to determine legality.

 WHY do you want to share and integrate data? For example, to: Track indicators at the population level Identify a target population Describe cross-enrollment patterns Identify geographic areas of greatest impact Evaluate program outcomes Improve services at the point of intervention Conduct mandated reporting 	 WHO do you want to share it with, and who conducts the integration? For example: Executive leadership Agency serving the same client Probation officers A community treatment provider A hospital emergency department A university-based researcher An agency-based analyst
 WHAT type of data do you want to share and integrate? Is it open, restricted, or unavailable? For example: Information that does not identify individuals Information that does identify individuals Information that might identify a person Health information Educational records Housing status Demographics 	HOW will you share the data? For example, provide: • Aggregate counts at the block group level • Credentialed access to source data • Access to public-facing dashboard • View-only access to data underlying a dashboard • Edit access to data underlying a dashboard • Row-level data with identifiers • Row-level data without identifiers

Why do you want to share and integrate data?

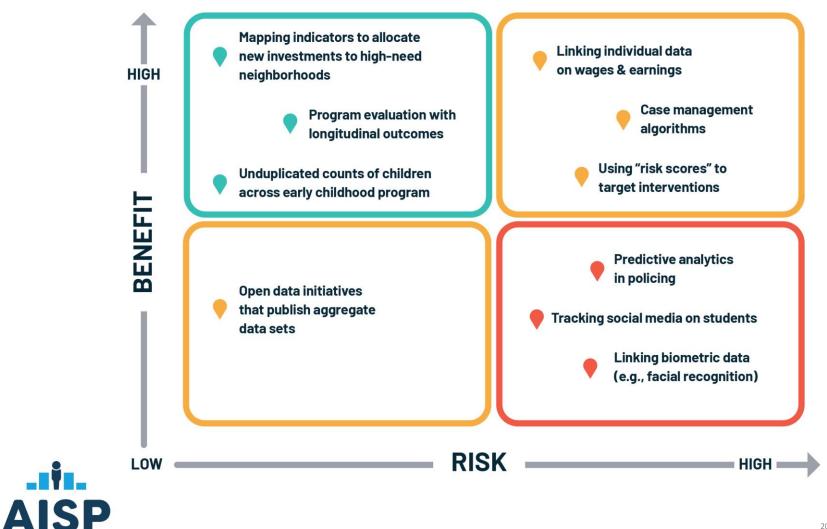
Who do you want to share it with, and who conducts the integration?

What type of data do you want to share and integrate? (Is it open, restricted, or unavailable?)

How will you share the data?



2. Is this ethical? Social License, Risk v. Benefit



3. Is this a good idea? Data availability, Resources, Action

- Are available data of sufficient quality to answer the question at hand?
- What action can be taken as a result of this analysis?
- How will programs/policies/lives be improved by this use of integrated data?
- What can reasonably be changed or improved based upon the findings? What cannot be changed?
- Has this question already been answered?
- Will the resources needed to conduct this integration yield more benefit than using these same resources for programmatic or direct funding?
- Who is conducting this integration and analysis? Do they have sufficient understanding of the program/policy/population that is being studied?
- Who is "asking" the question? Is this topic of interest to the broader community? Do community members, including those "in" the data, know about and support this work?



4. How do we know? Who decides? Data governance

Data governance: the people, policies, and procedures that support how data are managed, used, and protected.

Strong and inclusive data governance for cross-sector data sharing and integration should be:

- Purpose-, value-, and principle-driven
- Strategically located
- Collaborative
- Iterative
- Transparent



The Role of Data Owners, Data Stewards, and Data Custodians

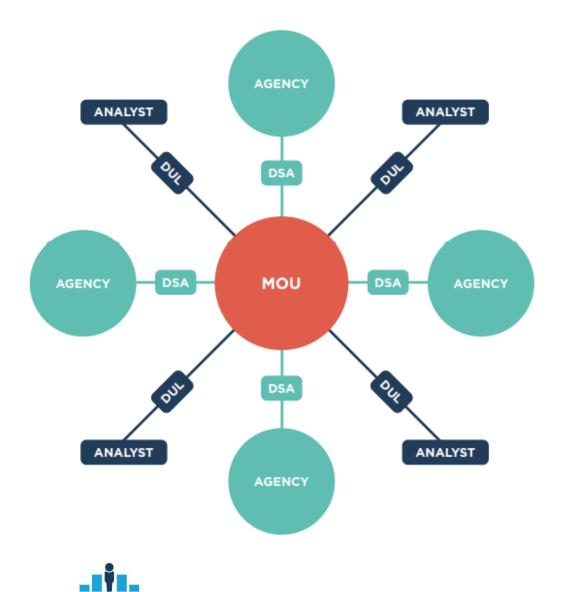
	Role in data sharing and integration process	Role within agency	
Data Owner	Accountable for the quality and security of the data and holds decision-making authority over access and use.	Typically agency leadership that has signatory authority	
Data Steward	Responsible for the governance of data, including transfer, alteration, storage, retention, disposition, classification, etc. Includes supporting established processes and policies for access and use, documenting limitations and bias, and maintaining metadata.	Typically subject matter experts and data analysts that regularly work with specific data	
Data Custodian	Responsible for the technology used to store, transport, and dispose of data, and for activities and safeguards required to maintain confidentiality, integrity, and availability. Communicates with Steward and Owner regarding any data management issues that pose a risk to data security and/or access.	Typically information technology staff or team	



How: The Legal Agreements

LEGAL AGREEMENT	PURPOSE	PROCESS	SIGNATORY
Memorandum of Understanding MOU Overarching process document signed on by all data partners	The MOU documents the purpose and governance process. The MOU will be signed by all data partners as they enter the collaboration. The MOU references the DSA, DUL, and relevant policies, and procedures for data access and use.	Drafted in partnership with legal counsel from all participating data partners	Lead agency/ies alldata partners
Data Sharing Agreement DSA Agency-specific to how data will be used for integration	The DSA includes the specific terms and conditions that govern how data are transferred, stored, and managed when shared and integrated. The DSA references the MOU and the DUL. This document is specific to data held by a data partner.	Template is drafted in partnership with legal counsel from all participating data partners. Completed according to specific data assets of the data partner. Reviewed and updated annually, or as agreed upon.	Lead agency/ies data partner
Data Use License DUL Data use-specific once data has been integrated	The DUL outlines the role and responsibilities of the data recipient. The DUL is often executed after the Data Request Form is approved. The Request Form and/or DUL should include: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUL must be executed prior to data access.	Template is drafted in partnership with legal counsel from all participating data partners. Once data request is approved, a DUL is executed.	Lead agency/ies data recipient

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We suggest agreements that are:

Tiered

Standardized but flexible

Transparent and Comprehensible

A Practical Example



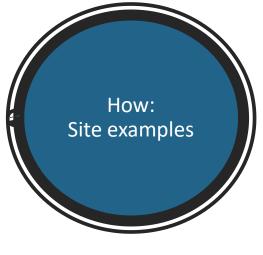
Lease = Legal Authority

MOU = Roommate Agreement

DSA = Individual Agreement re assets

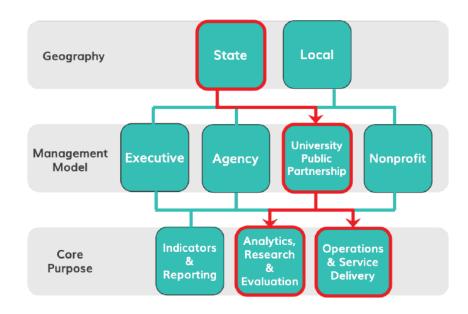
DUL = Details the use





The Linked Information Network of Colorado (LINC) is a collaborative partnership between the Colorado Governor's Office and the Colorado Evaluation Action Lab at The University of Denver. Their capacity for data integration helps strategically target services and benefits to vulnerable populations and identify opportunities to improve services, delivery, and opportunity.

Linked Information Network of Colorado (LINC) University Public Partnership, State



Learn more about LINC here.

Lead Agencies: Governor's Office and University of Denver

Data Partners: Birth and Death Records (CDPHE), Child Welfare (CDHS), Early Intervention (CDHS), Childcare subsidies (CDHS), EC Workforce Data (CDHS), Postsecondary Education (CDHE), Juvenile Justice Services (CDHS), Juvenile Courts (Judicial), Adult Court (Judicial), Denver Police Department (DPD), W-2 Employment and Wages (CLDE), Workforce Training Programs (CDLE), SNAP (CDHS), WIC (CDPHE), Denver Metro Homeless Initiative (HMIS), Denver Public Schools (DPS), see LINC Data Partners

Legal Authority: Contracts (e.g., EMOU, DSA, DUL)

Funding: State, federal, philanthropic partners, fee for service



Tribal data sovereignty

Tribal Data Sovereignty = inherent right of a nation to govern the ownership, collection, and use of its own data

Tribes have the authority to administer the collection, use and ownership of their own data

Tribes can enter into data sharing agreements with States

Tribes are subject to plenary power of the United States

Overview of appendices

Appendix A- Federal Law and Policy

Appendix B—Selected State & Tribal Laws, Policies and Rules

Appendix C—Sample Executive Orders and Authorizing Legislation Facilitating Data Integration

Appendices D-J—Sample Legal Agreements & Checklists



Questions?

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Check out our publications & quality framework: www.aisp.upenn.edu

Subscribe to our newsletter: <u>https://bit.ly/signupAISPnewsletter</u>



Implementing a Legal Framework for Data Sharing at the North Carolina Department of Health and Human Services

Paul Hogle, Associate General Counsel and Chief Records Office, NCDHHS





Overview of NCDHHS

- The North Carolina Department of Health and Human Services manages the delivery of health- and human-related services for all North Carolinians, especially our most vulnerable citizens – children, elderly, disabled and low-income families.
- NCDHHS is divided into 33 divisions and offices that fall under six broad service areas – Health, Opportunity and Well-Being, Medicaid, Operational Excellence, Health Equity, and Policy and Communications.
- NCDHHS also oversees 14 facilities: developmental centers, neuromedical treatment centers, psychiatric hospitals, alcohol and drug abuse treatment centers, and two residential programs for children.





NCDHHS Strategic Goals

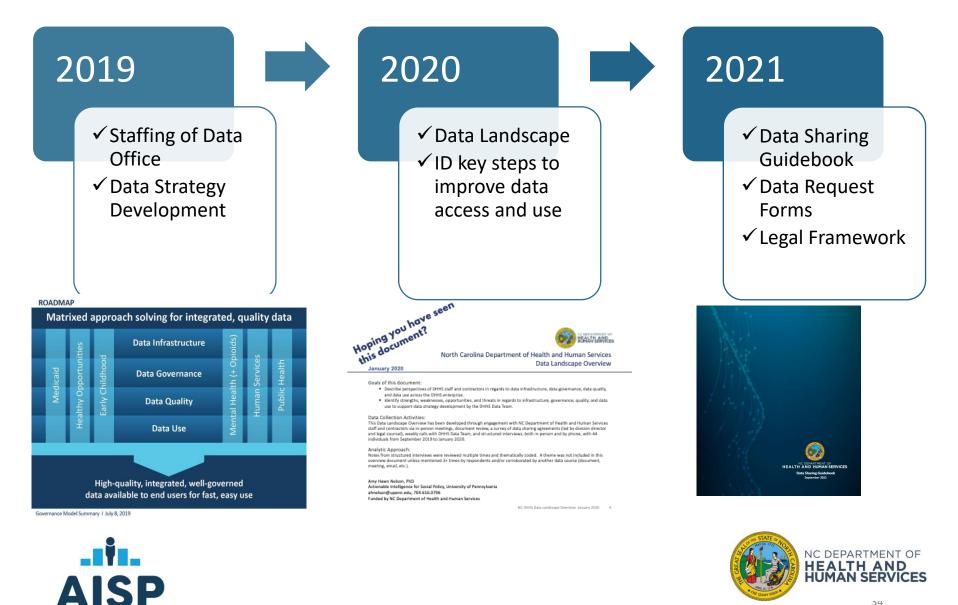
- 1. Advance health equity
- 2. Help North Carolinians end the pandemic, control the spread of COVID-19, recover stronger, and be prepared for future public health crises
- 3. Build an innovative, coordinated, and whole-person centered system
- 4. Turn the tide on North Carolina's opioid and substance use crisis.
- 5. Improve child and family well-being
- 6. Support individuals with disabilities and older adults in leading safe, healthy and fulfilling lives.
- 7. Achieve operational excellence by living our values belonging, joy, peoplefocused, proactive communication, stewardship, teamwork, and transparency.

Access NCDHHS' s Strategic Goals and 2022-2023 Strategic Plan Here: https://www.ncdhhs.gov/dhhs-strategic-plan-83121/download?attachment





Legal Framework History



Legal Framework History







The Framework – Foundational Legal Agreements

NCDHHS' s FOUNDATIONAL LEGAL AGREEMENTS

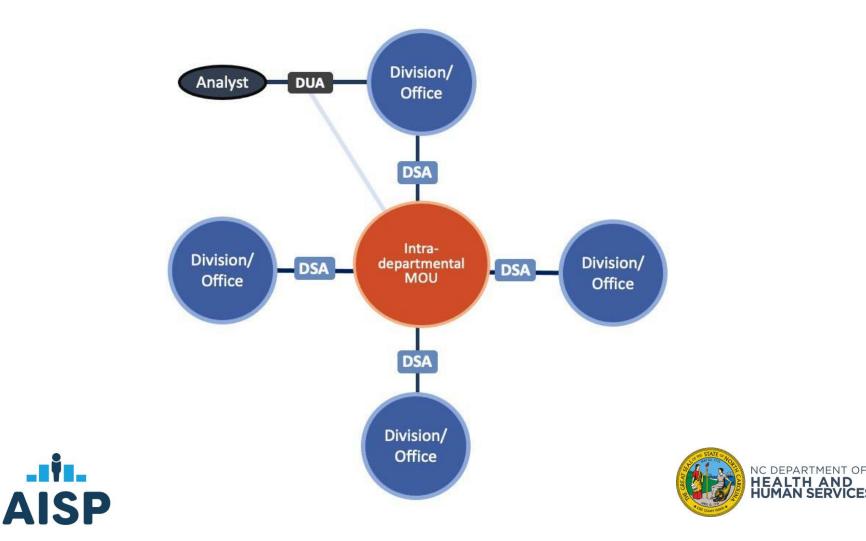
LEGAL DOCUMENT	PURPOSE	PROCESS	SIGNATORY
Intradepartmental MOU Overarching process and guiding principles document signed by all Divisions / Offices	 Documents the purpose and governance process. Is signed by all data partners as they enter the collaboration. Sets the stage where collaborators understand and agree on the basic premise that data use must be legally complaint, responsible, and only to the extent required. References the data sharing agreements, data use agreements, policies, and procedures for data access and use (e.g., NCDHHS Data Sharing Guidebook). 	Drafted by Data Office, reviewed by legal counsel, signed by Executive Leadership and updated through the NCDHHS Data Governance Council as needed.	All Division and Office Directors and Secretary's Office are parties to 1 agreement
Data Sharing Agreement Division / Office Specific	 The DSA includes the specific terms and conditions that govern how division- and office-specific data are transferred, stored, and managed when shared and integrated across the Department. The DSA references and reinforces the IMOU and the DUA. It is specific to Division and Office held data and incorporates language around use of data for administrative purposes, which if legally permissible is by default approved unless the data owner decides otherwise. 	Drafted by Data Office and Division/Office specific legal counsel. Reviewed and updated annually, or as agreed upon.	1 DSA per Division/Office Signed by Division and Office Director, the Data Office, and Information Technology Division
Data Use Agreement Data Request Specific	Legal counsel determines if a DUA is needed for a specific request. The DUA outlines the role and responsibilities of the data recipient. If applicable, this document is attached to the Data Request Form, which includes relevant fields, depending on the request, including: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUA must be executed prior to data access.	Data request is identified by type and reviewed appropriately based upon the type of request. Legal counsel determines if a DUA is applicable. If yes and request is approved, a DUA is executed.	DUAs are used as needed for use cases not covered by DSAs. Signed by Data Recipient and Data Owners (if applicable)



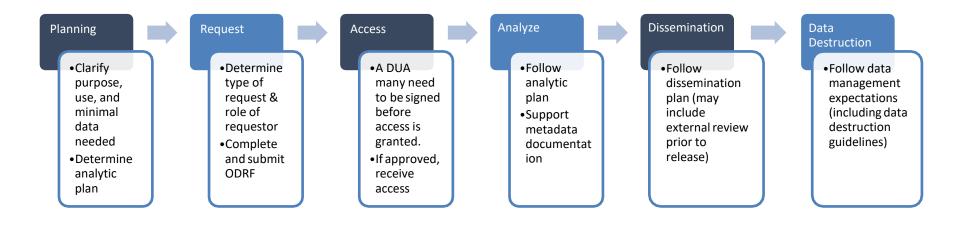




The below illustrates the intradepartmental legal agreements used to govern data access and use **across** NCDHHS Divisions and Offices and Programs.



Data Request Process for Data Requestors

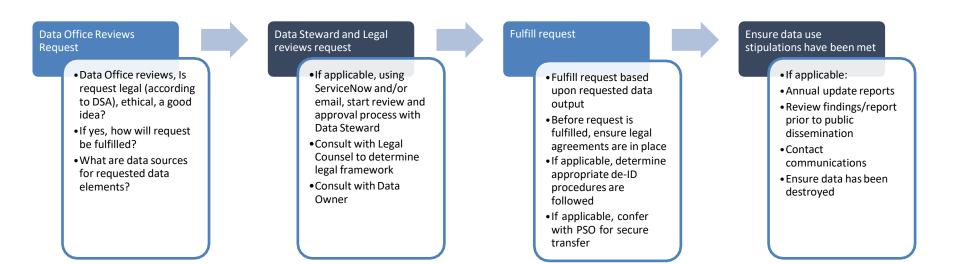






Data Request Process For Request Recipients

(including Data Steward, Data Owner or Designee, & Data Custodian)







NCDHHS Data Sharing Guidebook

NCDHHS Staff in collaboration with AISP created a guidebook for requestors and data owners that includes:

- The legal framework for internal and external sharing and integration, including an overview of relevant federal and state statute and rules
- General data classification guidance (open, restricted, unavailable) that correspond to North Carolina's statewide data classification system.
- Overview of department roles that support data sharing and use to better understand purposes and best legal practices
- Department priorities for data access & use
- NCDHHS high value data asset inventory
- NCDHHS data request process for 9 common pathways, operational requests being the most common
- Links to forms and templates.

Access NCDHHS Data Sharing Guidebook Here: https://www.ncdhhs.gov/about/administrative-office/data-office/data-sharing-guidebook





Key Points:

- Data use is only possible within a strong data governance model enabled by a robust legal framework.
- The framework encourages uniformity in process, drafting, and decisionmaking, which create efficiencies and reduces turnaround times, particularly for routine data uses.
- ➢Our legal framework corrects assumed barriers to data use while ensuring compliance with applicable law and policy.
- Compliance and risk mitigation are baked in from the beginning, not considered or added on the back-end.
- ➤The Legal Framework is intentionally flexible.
- ➤Legal Counsel are guiding the use of the framework.
- The legal framework directly impacts social license to operate, benefitting both legal operations and our programs.





URAPI 20021

NCDHHS Data Sharing Guidebook

Why a Guidebook for Data Sharing?	
Data Access and Use Across NCDHHS	
How to use this guidebook	
Data Use Priorities	
Requesting Data Access and Use	
Requesting Data from a NCDHHS Division or Office	
Purpose of Request Determines the Data Request Pathway	
Data Being Requested	
Requested Data Output	
Data Request Processes	
Know your role	
Data Owner (or Designee)	
Data Steward	
Data Custodian	
How Your Role Supports Data Access and Use	
NCDHHS Data Asset Inventory	
Legal Considerations	
Legal Framework	
Federal Laws Regarding Data Sharing	
Relevant State Rules & Regulations	
Considerations for Permitting Data Access and Use	
Prioritization of Data Requests	
Data De-identification	
Data Transfer	
Data Access and Use FAQs	
Terms	
Appendix	
Appendix A: Questions to guide data request pathways	
Appendix B. NCDHHS Terms and Conditions of Data Access and Use	
Internal Appendix for Legal Counsel	
A. Intra-agency Memorandum of Understanding	

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North Carolina Department of Health and Human Services NCDHHS Operational Data Request Form

Inte	Submit this form mal Use. Request #:	1 and	any questions by email to dataoff	ice@o	dhhs.nc.gov
1. 0	oes this data request align wit	h NC	DHHS priorities and support b	usine	ess intelligence of NCDH
	Yes		No		Unsure
2. V	Vhat is the main purpose of thi	s ope	erational data request?		
	Reporting		Quality Improvement		Evaluation
	Legal Implications		Health Care Operations, Payme	ent, a	nd Treatment
	Other: (please specify)				
3. V	Why does this request involve t I am requesting data from 1	ne N	I am requesting integrated		I am requesting identifia records for the purpose
		-			
	Division/Office, and there is not a Division/Office specific process		data from across NCDHHS Divisions/Offices.		integrating data from NCDHHS with another of source.
	I'm not sure. I would need to discuss my data request with		Other: (please specify)		source.
	someone.				
4. R	equestor's Contact Informatio	n			
Nar	ne of Requestor:				
	/ Role:				
Title	OHHS Division / Office,				
NC	nstitution / Agency				
NCI or li	nstitution / Agency quest is a part of contract with N	CDH	HS, and you are not NCDHHS st	aff, pi	ease check here.
NCI or li If re				aff, pl	ease check here.

5. Description of the Requested Data

How often does the Recipient want to receive data?

Daily
 Weekly
 Other



Questions?

Paul Hogle, JD Associate General Counsel & Chief Records Officer North Carolina Department of Health & Human Services Paul.Hogle@dhhs.nc.gov

Amy Hawn Nelson, PhD AISP Director of Training & Technical Assistance (member of NCDHHS Data Office since 2019) <u>ahnelson@upenn.edu</u>





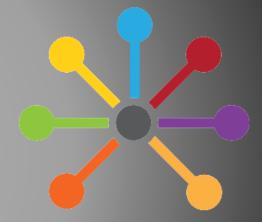
P20 WIN Legal Framework and Data Governance

Richard Gold Consultant to Connecticut Office of Policy & Management

P20 WIN

P20 WIN (The Preschool through 20 Workforce Information Network) is Connecticut's state longitudinal data system and is the mechanism by which data from multiple agencies are matched to address critical policy questions.

P20 WIN informs sound policies and practice through secure sharing of longitudinal data across participating agencies to ensure that individuals successfully navigate supportive services and educational pathways into the workforce.





OVERVIEW

- P20 WIN is a federated data system that has been operational since 2014. P20 WIN is used to answer policy questions, fulfill federal and state reporting requirements; support program review; inform school districts of postsecondary outcomes; provide employment and wage outcome data; and support research and analysis on a variety of topics.
- P20 WIN is codified <u>Sec. 10a-57g</u> of the Connecticut General Statutes and establishes decision-making processes while giving the P20 WIN Executive Board the ability to establish committees as needed.



ADMINISTRATION

Operating Group

 P20 WIN is administered by the Office of Policy and Management (OPM). As the Operating Group, OPM provides program management to support the continued operation and improvement of P20 WIN as a resource for the participating agencies and the State.

Data Integration Hub

The Data Integration Hub for P20 WIN is based at the Department of Labor, where all matching for approved requests happens.



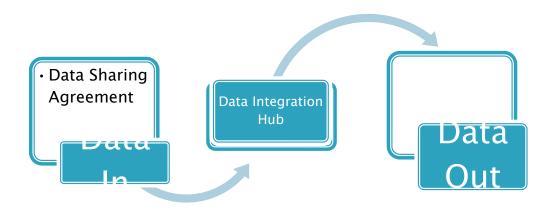
DATA PARTICIPATING AGENCIES

- Department of Labor (DOL)
- CT State Department of Education (CSDE)
- Department of Children and Families (DCF)
- Department of Social Services (DSS)
- Office of Early Childhood (OEC)
- Office of Higher Education (OHE)
- CT Conference of Independent Colleges (CCIC)
- CT State Colleges and Universities (CSCU)
- University of Connecticut (Uconn)
- CT Coalition to End Homelessness (CCEH)
- Department of Mental Health and Addiction Services (DMHAS)
- CT Technical Education and Career System (CTECS)
- Department of Corrections (DOC)
- Judicial Branch Court Support Services (JBCSSD)



Legal Agreements

- Enterprise Memorandum of Understanding (eMOU)
- Data Sharing Agreement (DSA)
- Each document has different signatories and serves different purposes.





Enterprise Memorandum of Understanding (eMOU)

- Outlines the rules of the road that all participating agencies agree to.
- The eMOU outlines the governance structure of P20 WIN, the technical processes, security and privacy standards.
- Does <u>not</u> include regulations and laws that are specific to a particular dataset/state agency.
- Signed by executive leadership for each Participating Agency.



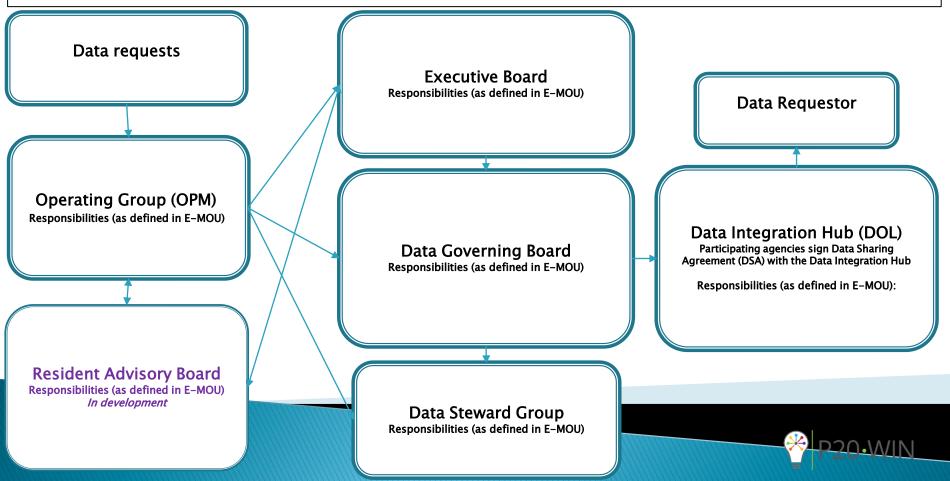
Data Sharing Agreement (DSA)

Adapted & combined the AISP Data Sharing Agreement and the Data Use License into a single document that includes all parties to specific, approved data request

- Clearly details what data are being shared and how the data can be used.
- Templates include provisions concerning access and dissemination for specific datasets at each agency.
- The P20 WIN DSA includes:
 - Requirements to access to specific data
 - Specific confidentiality/security requirements and disclaimers
 - Time limits



P20 WIN 2.0 – Proposed Legal and Governance Framework



P20 WIN Governance Structure

Executive Board

(Leadership from participating state agencies) **Responsibilities:**

- Advances vision, mission and purpose
- Advance priorities for research, evaluation and case management
- Champions system implementation, maintenance and improvement
- Fiscal and policy responsibility

Data Governing Board

Responsibilities:

- Establishes data governance policies
- Establishes process for requesting, processing, and downloading data
- Reviews and approves requests for data
- Provides agency data
- Sets parameters for data access, dissemination, and destruction

Operating Group

Responsibilities:

- Develops and submits budget requests
- Program management and operations
- Financial and back-office support
- Convenes governing bodies
- Receives and reviews data requests
- Track data use and enforce data

destruction policy

Data Integration Hub

Responsibilities:

- Cleans and de-identifies data, and sends data back to requester
- Documents receipt and destruction of files
- Conducts cross-agency data matching/linking
- Integrated case management

Data requests

For: Research, cross-agency link/match, case Management From: State agencies, academics, nonprofits, etc.

Data Steward Group Responsibilities:

- Implements data system policies
- Define data standards, data cleaning processes, metadata
- Evaluate data quality and data matching

Resident Advisory Board

(in development)

- Recipients & consumers of state services, parents, youth
- Advises state agencies in earning public trust.
- Reviews requests for equity and disparate impact on clients/ consumers/ families