

# Understanding and Addressing Regulatory Barriers to Enacting Integrated Data Systems

Planning to develop or expand an integrated data system (IDS) requires navigating many federal and state laws and policies that can limit or restrict the uses of the integrated data. Although these various regulations were enacted to protect privacy, they were not generally designed in coordination with each other, so they can unintentionally create barriers that prevent an IDS from achieving full effectiveness and success.

An IDS refers to the system in which data from various sources are brought together as an integrated whole. Linking data across various public agencies can create a more holistic picture of outcomes for people in education, health care, the workforce, and beyond. This clearer picture enables a better understanding of the complex needs of individuals and communities, which can inform the design of new strategies and interventions to address those needs and the evaluation of the effectiveness of programs and policies on desired outcomes.

This document provides information for interested parties about

- the sector-based national and state laws and policies that impact linking cross-sector data used in IDSs,
- key steps for identifying and addressing the regulatory barriers for IDSs,
- options for policy changes that can mitigate or eliminate the regulatory barriers to data integration efforts, and
- case studies from three states.

## INTEGRATED DATA SYSTEMS

connect data over time and across sectors to provide data insights that support leaders in answering policy questions, directing resources, and better supporting individuals.



## Sector-Based Regulatory Barriers in the United States

Strong protections to ensure privacy and appropriate guardrails to prevent misuse and breach of information are critical. Because of the sectoral approach to privacy in the United States, many federal privacy laws are based on the industry in which the information originates. For example, laws related to education records often place responsibility with education agencies, such as K-12 schools or colleges, while responsibility under laws related to health records lies with health and human services organizations, such as hospitals or health insurance providers. Federal laws tend to be permissive in describing what industries are allowed to do when integrating data from these various sectors. States, however, have enacted privacy laws that may have unintended consequences that may limit the ability to effectively build an IDS. Current regulatory frameworks generally did not envision the critical need and urgency for developing IDSs, which requires navigating complicated federal, state, and sometimes also local laws and requirements across sectors and levels of government.

An IDS, by its very nature, is a multisector initiative involving cross-industry information. Data linked from various sectors support data systems that provide information and insights to improve the education, health care, and workforce supports within states. Though federal privacy laws often set the minimum protections that must be in place, state laws that apply to data privacy vary. For instance, some state laws restrict the use of specific sectors of data in IDSs, while others restrict access to or reporting on the data gathered by an IDS. This inconsistency creates problems for researchers, policymakers, and others whose efforts are dependent on accessing and using key information from IDSs.

However, IDSs can be appropriately implemented if they ensure proper security and privacy controls that align with state and federal regulatory requirements. Doing so requires understanding the legal framework in which the IDS operates, which sheds light on where regulatory barriers may exist and how to best address them.

## Steps for Identifying and Addressing Regulatory Barriers

### Build and Maintain Relationships

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To develop a network of support for the IDS, it is useful to build and maintain relationships with key sector and agency players, including policymakers, who contribute to and use the IDS. These contributors and data consumers are the champions who can advocate on the IDS's behalf. Consider the following:

- What research, analyses, or information will be useful to each sector that contributes to the IDS? Developing meaningful resources for the contributing sectors will ensure their continued participation and advocacy.
- Are there gaps in knowledge that the IDS can fill? What products or information can the IDS develop that fills those gaps? Consider how to ensure that data are informational as well as actionable.
- Consider what questions the communities, parents, and residents of the respective state need answers to—answers that multisector, linked data could provide.

## Demonstrate the Value of Integrated Data Systems

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Identifying how the purposes, goals, or outcomes of the IDS align with state priorities is a critical step for its development and sustainability. Robust community engagement, solid funding and planning, expert management, and many other factors add to the IDS's success. Consider the following:

- What are state legislators' and policymakers' greatest needs that multisector linked data can provide insight into? Consider how the identified needs align with the state's goals and how much time will be needed to analyze the data to inform decision-making.
- What areas can or should be legislatively mandated? What components in legislation will make it easier to operate the IDS? What legislation may make it harder?
- What are the biggest concerns from opponents in the design, purpose, or use of the IDS? Could those concerns be addressed by the IDS through regulatory changes, policies and procedures, or other existing governance structures?

## Use the Legal Framework Approach

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Understanding your own regulatory environment starts with identifying the legal framework, which involves delineating the privacy and security requirements involved in linking data and establishing access and use restrictions for the data in the IDS. As part of this process, clearly articulate what your IDS will and will not collect based on existing federal and state laws. Legal frameworks for IDSs in the same state may vary based on the partners who contribute data. Having a sound understanding of the limitations imposed by state laws aids in managing expectations for the overall mission of the IDS. (See *Using a Legal Framework Approach for Integrated Data Systems* for more information about this approach.)

## Consider Options for Changing Regulatory Barriers

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Policymakers need to consider and carefully analyze the impact of any planned requirements to ensure responsible and efficient use of data in an IDS. Overly restrictive regulations can have unintended consequences. These consequences can be avoided by including nonpartisan, privacy-minded professional legal assistance in implementing the IDS to carefully weigh the utility and usefulness of appropriately protected, linked, multisector data. Many states have been able to proactively address concerns related to

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restrictive data regulations without placing restrictions on the scope or purpose of the IDSs or limiting the data that IDSs have access to.

Over time, as understanding of the need for IDSs deepens, it might be appropriate for IDSs to work directly with contributing agencies and policymakers to consider modifying or changing regulations that are creating barriers. For example, the coronavirus pandemic highlighted the need for data integration across sectors to fully comprehend the impact of the pandemic and identify the supports needed to assist communities. Consider the following to determine if changing regulatory barriers is appropriate:

- Is there support from key sectors and state policymakers to change the regulatory barrier through legislation? Is support oriented around a specific topic or need (i.e., the coronavirus pandemic) that could be leveraged to build support? Consider the ways to show the value of the IDS.
- Are there simple changes that would create pathways through regulatory barriers? Since it can be hard to garner support for large legislative change, consider minimal changes that may eliminate or reduce barriers and strengthen the use of integrated data.
- How might you mobilize support for such legislative change?

## Case Studies of Effective State Policy

### California

#### California uses regulatory authority to enact comprehensive P–20W data policy

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California followed the steps outlined above—building relationships, demonstrating alignment with state priorities, using a legal framework—to eliminate barriers and enact an evidence-based P–20W data policy that centers equity and best practices. The P–20W data system securely brings together data from across the early childhood, K–12, postsecondary, and workforce sectors. Data from these sectors are crucial to providing those closest to students with the information they need to help students navigate their unique journeys from education to careers. While implementation is key to any initiative's ultimate success, good policy matters. In California's case, an effective, evidence-based policy has positioned the state as a national leader in using data to serve individuals.

See [additional information on California's success](#) from DISC partner, Data Quality Campaign.

### Nebraska

#### Nebraska connects workforce and education information

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Nebraska legislators passed the Nebraska Statewide Workforce and Education Reporting Act in 2020. This law requires the state to connect workforce data from the Department of Labor to the existing state longitudinal data system. With education and workforce data side by side, students, parents, policymakers, institutional leaders, and researchers have more of the information they need to better understand student pathways through the education system and the workforce, make informed decisions, and support students' long-term career success.

## Kentucky

### Cascading legislation creates needed regulatory authority

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Kentucky did not have existing laws that permitted a statewide IDS. However, with a thoughtful approach, Kentucky was able to implement a framework of laws to govern an IDS, the Kentucky Center for Statistics (KYSTATS).

The first law (focused on implementation from prekindergarten through postsecondary education) set definitions for a variety of terms relevant to the development of the IDS, such as “education data” and “workforce data.” That was followed by a law that created the Office for Education and Workforce Statistics. That law permitted the collection of education and workforce data and provided for the certification and ownership of data as well as funding for staff and operations of the IDS. Another law set

the duties of the Office for Education and Workforce Statistics. The next law established the Board of Kentucky Center for Statistics, which guides the work at KYSTATS through developing a research agenda, providing oversight, and enforcing compliance. The final law created a Council for Educational Research that advises the board and KYSTATS on the research needs of colleges of education for conducting education research.

This comprehensive approach created intuitive supports and safeguards that help KYSTATS implement its mission. Ultimately, Kentucky’s approach has provided immense value for its policymakers, researchers, and state and local agencies.

See additional information on [KYSTATS laws](#) on their [website](#).

## How the Data Integration Support Center Can Help

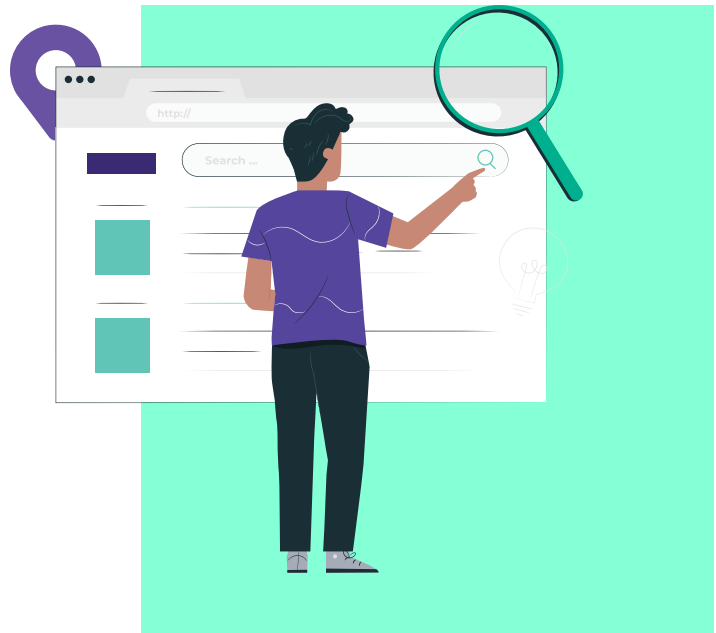
The Data Integration Support Center (DISC) at WestEd can support IDS implementation that identifies and addresses common regulatory barriers. DISC offers technical assistance to public agencies free of cost, including the following:

- providing information to educate and raise awareness of the restrictions caused by current and proposed laws and the impact of those restrictions
- facilitating IDS environments that include appropriate privacy protections and security for personal data aligned with the IDS legal framework
- developing model policies and procedures that support IDS access for researchers while also ensuring the privacy and security of the systems
- providing training and resources for researchers on accessing and using an IDS within legal and regulatory frameworks and using appropriate disclosure avoidance methods

## Resources

The following are some useful resources to help organizations understand and address regulatory barriers when creating an IDS:

- [\*Accessing SLDS Data: Innovative Solutions to State-Specific Security Controls \(March 2020\)\*](#): This SLDS [State Longitudinal Data System] Spotlight from the National Center for Education Statistics at the Institute of Education Sciences highlights two states with laws that strongly regulate data access. It describes how these state agencies have adapted to comply with state requirements while continuing to meet their reporting and operational needs.
- [\*Education Data 101: A Briefing Book for Policymakers\*](#): While focused on state longitudinal data systems (which link state education data over time to provide a complete academic history for each student), this briefing book from the Data Quality Campaign provides useful information on major topics related to data use to provide insights and drive improvement.
- [\*Quality Framework for Integrated Data Systems\*](#): This resource from Actionable Intelligence for Social Policy (AISP) outlines five key components of quality data in IDSs. This resource includes legal and governance frameworks to assist IDSs in understanding the regulatory barriers that may exist.



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