The Integration of Early Childhood Data

State Profiles and A Report from the U.S. Department of Health and Human Services and the U.S. Department of Education

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This report was prepared at the request of the Early Learning Interagency Policy Board, which was established by the U.S. Department of Education (ED) and the U.S. Department of Health and Human Services (HHS) to improve program coordination and quality across federally funded early learning and development programs serving children from birth through age eight.

The report was written by a team that included multiple offices in both agencies, led by Erica Lee in the Policy and Program Studies Service in ED and Lindsey Hutchison and Kimberly Burgess in the Office of the Assistant Secretary for Planning and Evaluation in HHS. Contributing offices in ED included the Office of Planning, Evaluation and Policy Development; the Office of Elementary and Secondary Education; the Institute of Education Sciences; the Office for Special Education and Rehabilitative Services; the Office of Management; and the Office of the General Counsel. Contributing offices in HHS included the Office of Human Services Policy in the Office of the Assistant Secretary for Planning and Evaluation; the Office of Early Childhood Development, Office of Head Start, and Office of Child Care in the Administration for Children and Families; the Maternal and Child Health Bureau in the Health Resources and Services Administration; and the Center for Medicaid and CHIP Services in the Centers for Medicare and Medicaid Services. Additionally, the U.S. Department of Agriculture’s Food and Nutrition Service contributed to the report.

Several early childhood integrated data system experts provided valuable support and feedback, including Missy Coffey (State Longitudinal Data Systems State Support team), Carlise King (Early Childhood Data Collaborative), Kathy Hebbeler and Donna Spiker (Center for IDEA Early Childhood Data Systems), and Elizabeth Dabney (Data Quality Campaign).

Finally, the authors of this report are grateful to the early childhood data system managers in the eight states included in this report: Georgia, Maryland, Minnesota, North Carolina, Oregon, Pennsylvania, Rhode Island, and Utah. Without their time and support, this report would not have been possible.
Purpose
This report is intended to help states refine their capacity to use existing administrative data\(^1\) from early childhood (EC) programs to improve services for young children and families. Linking data collected across early childhood programs can help program leaders and policymakers better understand the needs of the children and families these programs serve as well as support continuous program improvement, innovation, and research. Integrated early childhood data can help to answer important questions related to program access, participation, quality, and their association with child outcomes. These answers can, in turn, inform how federal and state funds support young children’s early learning, health, and development across a range of programs and services; impact resource allocation decisions; allow for examination of patterns in service use; identify areas for quality improvement and innovation; and improve the coordination of service delivery across systems at both the state and local levels.

The first section of this report includes a vision for integrated EC data and explains how states can use integrated data to inform decisions. The second section covers key considerations when integrating and linking EC data based on the best practices from the field and lessons learned from eight states profiled that are actively engaged in developing integrated EC data systems. The report concludes with more detailed information about the eight profiled states. Because states and localities face challenges when attempting to integrate EC data, the U.S. Department of Education (ED) and the U.S. Department of Health and Human Services (HHS) have funded a variety of research projects and technical assistance (TA) centers to assist states in these efforts. Many of the resources that have been developed through these initiatives are highlighted in this report and listed in Appendix A. Appendix A also includes information on recent federal investments and opportunities to further the development of integrated data systems, federally-funded toolkits, and other useful resources.

Background and Vision
Despite many important federal, state, and local investments in early care, education, and public health, many young children do not receive the support they need to be adequately prepared for school. In fact, achievement and development gaps can be detected in children as early as nine months of age, and these early health and educational disparities often persist throughout a person’s lifespan.\(^2\) Early investments in health, family support, and high-quality early learning opportunities have been shown to provide both short- and long-term positive impacts on children’s future outcomes that can provide long-term benefits to society.\(^3\)

Because many different programs and services may touch the lives of children and families in the early childhood years, it is difficult to obtain a full picture of the early childhood landscape or understand the relationship between individual programs and outcomes without integrated data. As states and localities work to ensure that all children are supported in their early childhood years and ready for school, integrated data can be used to inform policy and have honest conversations about: 1) the availability and quality of services currently available to young children and their families; 2) how to improve the quality

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\(^{1}\) In this document, *administrative data* refers to information programs routinely collect about individual children, families, and staff to deliver program services and meet program, funding, or legal requirements. This could include, but is not limited to, demographic information (e.g., race/ethnicity, date of birth) on children and families, child attendance, results of child screenings or assessments, staff qualifications, and/or program characteristics.


Many states have already invested in developing integrated data systems to help answer early childhood policy questions and support continuous improvement in services. When fully functional, these systems, often called Early Childhood Integrated Data Systems (ECIDS), connect, integrate, secure, maintain, store, and report information from a variety of EC programs and services. Through an ECIDS, EC programs can share data related to the children and families the program serves, personnel, and the characteristics of the program or services offered. In some cases, administrative data that is integral to supporting early childhood development may not be integrated into – or a part of – an ECIDS, but instead linked to the ECIDS. This report refers to “integrated data” and “linked data” to make clear that states and programs can benefit from broad types of data connecting together, regardless of where the data may be housed and the mechanism used to connect data.

Once an ECIDS is fully functioning, many possibilities around data use emerge. For example, some states use their ECIDS to generate standard, aggregate-level reports for individual EC programs across the state on the children they serve. Other states have made efforts to integrate data in a way that can support more real-time case management and improve efficiency in enrollment and service delivery across programs.

Some of the important policy questions that linked and integrated data can help answer are:

- How many children in the state are participating in EC programs and services (i.e., a distinct count of children receiving EC programs and services)?
- What different combinations of EC programs and services do children receive, and how are these combinations related to child outcomes at kindergarten entry and later in school?
- Where are there gaps in access to and participation in high-quality EC programs and services?
- For children who participated in EC programs and services, what are the relationships among staff characteristics, qualifications, professional development, and child outcomes?
- What other kinds of social and health services are families of young children accessing (e.g., Temporary Assistance for Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP), Medicaid, job training)? Are there families that may qualify for these services that are not currently accessing them?

As discussed more extensively in Appendix A, federal funds have supported states in their efforts to develop ECIDS. In particular, federal support provided through the Race to the Top-Early Learning Challenge (RTT-ELC) program, administered by ED and HHS, and ED’s Statewide Longitudinal Data Systems (SLDS) program have supported state progress in building ECIDS. Twenty-six states have received SLDS funds to incorporate early childhood data into their SLDS or to develop or enhance their ECIDS, and 16 states that received RTT-ELC funds committed to using those funds to develop or enhance their ECIDS (see Figure 1). SLDS-funded states focused their work on EC data to varying degrees. Additionally, many states are using their own funds to develop ECIDS. The profiles included in this report highlight some of the exciting progress made in various states across the country.
Many states are working to integrate data vertically to K–12 public school data and horizontally across programs that serve children during the early childhood period. By 2015, 32 states had linked their K–12 data to some of their early childhood data. As more EC data are linked to K–12 data, EC programs will be able to learn, in the aggregate, how children they served are progressing through school. For example, a program could learn how children who participated in their program fared on kindergarten entry assessments. Integrating data horizontally can allow states and localities to understand the range of services and programs that reach children and families during the early childhood period. Additionally, states and school districts could use this information to better understand the EC experience of arriving kindergarteners and to determine if and where additional early childhood program investments are needed.

An ECIDS that is integrated horizontally could also serve as a case management system and help improve coordination and service delivery. For example, horizontal data sharing could allow authorized users at an EC program to know whether a child in their care has health insurance, is up-to-date on immunizations and developmental screenings, or has been enrolled in early intervention services. Most ECIDS do not yet have the capacity to provide real-time reporting back to EC programs to improve service delivery. However, many states have horizontally integrated their EC data to help answer policy questions, and some states are using horizontally-linked data to streamline enrollment and eligibility determination processes. Investments in ECIDS and alignment across early childhood data systems can establish a more comprehensive understanding of how to organize early childhood systems and programs to achieve improvements in kindergarten readiness and meet other program and policy objectives. While states have made progress in these areas, many states are still working to integrate the range of program data they would need to answer some of the more sophisticated policy questions they seek to understand.

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ECIDS and efforts to integrate data across programs serving children and families in the early childhood period will also allow states and local educational agencies (LEAs) to meet new federal reporting requirements and improve performance outcomes required by the amended Elementary and Secondary Education Act (ESEA); the reauthorized Child Care and Development Block Grant Act (CCDBG); the new Head Start Program Performance Standards; the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program; and the Individuals with Disabilities Education Act (IDEA) program. Each of these programs has reporting requirements or performance measurement systems that rely upon early childhood data. Examples of these federal EC data reporting requirements are listed below:

- The amended ESEA requires states and LEAs to include on their report cards the number and percentage of children enrolled in preschool programs. Additionally, the amended ESEA requires that each LEA receiving Title I funds, regardless of whether it operates a Title I preschool program, must develop and implement a systematic procedure for receiving records of preschool children.

- Under the reauthorized CCDBG law, each state will be required to report information on its activities to improve the quality of child care across settings and the measures it will use to evaluate progress in improving the quality of child care programs and services in the state. States will also report quality information for each child care provider that receives funding from the Child Care and Development Fund (CCDF), and those states with Quality Rating and Improvement Systems (QRIS) will include QRIS participation level in these data submissions. Additionally, states will be required to report on the number of children served by IDEA that also benefit from the CCDF program.

- Under Parts B and C of the IDEA, states are required to report on the settings where young children with disabilities receive services. These data collections require states to report on the number of young children with disabilities who receive services in particular settings such as “regular early childhood programs” under Part B of the IDEA and “community-based settings” under Part C of the IDEA.

- The new Head Start Program Performance Standards regulation, released in September 2016, requires Head Start programs to coordinate with state education data systems, including SLDS and ECIDS, to the extent practicable, if the program can receive similar support and benefits as other participating early childhood programs. The standards also require that Head Start programs participate in state QRIS, and programs will need to meet these QRIS data requirements by August 2017.

- Similarly, integrated data can provide information needed for public health agencies and other administrators of the MIECHV program to report performance measures demonstrating improvements in kindergarten readiness or other relevant benchmark areas.

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5 ESEA section 1111(h)(1)(C)(viii)(II)(aa), (2)(C)
6 ESEA section 1119
7 The IDEA 2014-15 data collection defines “regular early childhood program” for the IDEA preschool data collection requirement as “a program that includes a majority (at least 50 percent) of nondisabled children … and may include, but is not limited to: Head Start; kindergartens; preschool classes offered to an eligible pre-kindergarten population by the public school system; private kindergartens or preschools; and group child development center or child care” and a “community-based setting” for the IDEA Part C data collection as a setting in which services are primarily provided where children without disabilities typically are found … including but not limited to child care centers (including family day care), preschools, regular nursery schools, early childhood centers, libraries, grocery stores, parks, restaurants, and community centers (e.g., YMCA, Boys and Girls Clubs).
Key Considerations for Integrating and Linking Early Childhood Data

Once a state’s leadership — which may include the state legislature, the governor, or agency leaders — decides to fiscally and politically support integrating and linking early childhood data to enable the many useful functions it can serve, state staff are faced with the multi-stage task of bringing the vision to fruition. Two useful resources for those groups seeking to develop an ECIDS for their state include: 1) the SLDS State Support Team’s (SST)8 Early Childhood Integrated Data Systems Toolkit; and 2) the Center for IDEA Early Childhood Data Systems (the DaSy Center)9 System Framework. These resources outline in detail the characteristics of a high-quality ECIDS as well as the steps involved in developing one.

The key considerations for integrating and linking EC data listed below draw from these two frameworks, as well as from common lessons learned from the experiences of eight states actively engaged in the process of developing, improving, and using their own ECIDS. HHS and ED staff selected these eight states following discussions with experts from the field10 and HHS and ED leadership. State profiles, included at the end of the report and hyper-linked throughout the report, provide an overview of the states’ work, including lessons they have learned.11 These frameworks and state experiences suggest that states consider the following as they move forward in developing an ECIDS or linking data across early childhood systems:

1. Develop a purpose and vision for the ECIDS;
2. Create strong data governance processes;
3. Engage stakeholders meaningfully;
4. Ensure data ownership is clearly included in vendor contracts;
5. Ensure children’s and parents’ rights to data privacy;
6. Ensure data security;
7. Ensure data quality and comparability across data systems;
8. Build capacity to analyze and use data;
9. Capitalize on other data integration efforts; and
10. Integrate and link broad types of early childhood data together.

1. Develop a Purpose and Vision for Early Childhood Data Integration

Once a state leadership team determines it is interested in integrating data, the state should develop a clear purpose and vision for the ECIDS. The purpose statement should describe the reasons the state is building the ECIDS and intended short- and mid-term results the state aims to achieve. For example, stakeholders in the state may aim to have the capacity to answer a set of key policy and research questions that require using data from multiple programs; however, in the short-term they may only be able to have a core set of data integrated to answer their highest-priority questions. The vision statement should be an aspirational description of how the state will use the integrated data to inform policy decisions or enhance services to improve outcomes for young children. The vision statement should be broad enough that the ECIDS could continue to expand and develop to include new sources of data as knowledge and experience grow; however, if the state seeks to expand the ECIDS to include a source of data that was not originally included in the purpose and vision, the state should revisit and, if necessary, revise the purpose and vision. As described in the subsequent section on stakeholder engagement, stakeholders at both the state

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8 ED’s SLDS State Support Team (SST) is composed of experienced state data systems experts whose primary objective is the direct support of all states in their development and use of SLDS.

9 The DaSy Center provides technical assistance to state agencies to build capacity in developing or enhancing data systems for Part C early intervention and Part B preschool special education programs supported through the IDEA, including support for incorporating IDEA data in the development of ECIDS.

10 ED and HHS staff consulted with Missy Coffey from the SLDS SST, Carlise King from the Early Childhood Data Collaborative, and Kathy Hebbeler and Donna Spiker from the DaSy Center.

11 The state profiles are illustrative examples of select key considerations. Neither ED nor HHS specifically reviewed all of the policies and disclosures for each of these states, and this document does not represent review of such policies and procedures.
and local levels should be involved in setting the purpose and vision (e.g., *What questions should the integrated data be able to answer? How will the data be used?*). Considering the timeline for implementing the vision and setting milestones to track progress towards that goal may also help the state define and move forward in this work.

Resources that may assist states and local jurisdictions with setting a purpose and vision include:

- The SLDS SST ECIDS Toolkit on Purpose and Vision, which provides an overview of the purpose and vision development process; and
- The DaSy Framework, which outlines elements for states to consider related to the *Purpose or Vision* of a data system.

2. **Create Strong Data Governance Processes**

Data governance involves the development of policies and procedures for managing and using data, usually by a group of stakeholders known as a *data governance body* or *data governance entity*. The data governance body should include a range of stakeholders, such as representatives from agencies serving children, local EC programs, providers and caregivers, parents and families, researchers, and professional organizations. The data governance body develops policies and procedures related to data records management, data quality, data privacy, data security, and data access. As each of these topics may be handled differently across programs and services, they are particularly important for data governance bodies of integrated data systems to consider.

Effective data governance will help states ensure that high-quality data are securely available to identified end-users such as decision makers and researchers in a timely fashion, while also protecting the privacy of the individuals whose information is being shared and integrated. The data governance body is responsible for developing a process for end-users to access data from the ECIDS. The data governance body can help states address this issue as well as other key considerations discussed in subsequent sections of this report, such as stakeholder engagement, data ownership, data privacy, data quality, and data use.

There are several federally-funded resources available to assist states with developing effective data governance structures and procedures, including:

- The Privacy Technical Assistance Center (PTAC), which has created a *Data Governance Checklist* that identifies best practices for state or local organizations that are establishing or maintaining a data governance program;
- The SLDS SST, which provides an *introduction to early childhood data governance* for states and other key stakeholders;
- The DaSy Center’s Early Childhood Data Systems Framework, which includes a component focused on *key elements of effective data governance and management*; and
- HHS’ *Building Capacity to Use Linked Administrative Data* Project that has developed a guide for data governance for local EC programs to use as they consider sharing data with states or other agencies.

3. **Engage Stakeholders Meaningfully**

In order for any data system, and especially an integrated data system, to be useful and meaningful, various stakeholders need to be engaged in an on-going manner throughout the process of developing and

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12 Head Start uses the term “data management;” see 1302.101(b)(4) of the Head Start Program Performance Standards. The current report uses the term “data governance.”

13 The Privacy Technical Assistance Center (PTAC) is funded by the U.S. Department of Education and serves as a resource for education stakeholders to learn about data privacy, confidentiality, and security practices related to student-level longitudinal data systems and other uses of student data. See below for additional information on PTAC.
using the system. Depending on the particular early childhood data integration effort in a given state, key stakeholders may include: data owners (e.g., state agencies, local jurisdictions, local EC programs and providers), data users (e.g., state and local policy makers, program directors, researchers), parents and families, data vendors, foundations or other funders, early childhood advocacy groups, and professional organizations (e.g., State Head Start Associations, Head Start State Collaboration Offices, professional associations that support the Early Care and Education (ECE) workforce). Some of these stakeholders may be members of the data governance body while other stakeholders will work with the data governance body.

Stakeholders should be engaged early in the process of developing and enhancing an ECIDS to determine the purpose of the integrated data system and to discuss issues regarding data privacy, access, and use. Stakeholders should be involved in guiding the broad goals of the data integration efforts (e.g., *What questions should the integrated data be able to answer? How can we use the linked data to improve efficiency?*), as well as specific goals associated with the integration of new data sources (e.g., *What specific data elements should the state integrate from Head Start programs?*). Data owners are more likely to view the effort to integrate their data as worthwhile if they understand how their program — and the children they serve — will benefit by linking program data to an integrated system such as an ECIDS. Additionally, data owners need to understand — and provide input on — how their data will be safeguarded, the conditions under which their data may be shared with analysts or researchers and the procedures for sharing their data, and the types of reports that the state will make available.

Minnesota, North Carolina, and Pennsylvania are examples of states that spent time carefully explaining to stakeholders what types of questions the ECIDS would and would not be able to answer (e.g., the systems would not allow for local programs to learn about individual children). When Minnesota worked to integrate Head Start data into its ECIDS, it included local Head Start leaders in its governance structure to ensure that the ECIDS would be able to address questions to which Head Start leaders wanted answers. North Carolina also wanted to integrate Head Start data into their ECIDS and in doing so worked closely with its Head Start State Collaboration Office to talk with local Head Start programs about the benefits of integrating data for both the state and for the Head Start programs. In Pennsylvania, there was some hesitation from local providers about integrating early intervention and preschool special education data, so the state facilitated leadership meetings six times a year between local IDEa Part C coordinators and local IDEa Part B, Section 619 coordinators. As a result of this in-depth engagement, local providers saw the benefits of working together for a unified birth through five early intervention data system. In addition, Pennsylvania developed a guide for parents that describes the benefits of sharing data, the types of data that are collected, and privacy safeguards in place.

There are several federally-funded resources available to assist states with successfully engaging stakeholders in early childhood data systems development. The first two resources listed below were originally developed for IDEa Part C early intervention and IDEa Part B, Section 619 preschool special education programs but are relevant for all early childhood data systems. These resources include:

- The DaSy Center’s Early Childhood Data System Framework, which includes a Stakeholder Engagement component;
- DaSy Center’s modules on Stakeholder Engagement; and
- The SLDS SST ECIDS toolkit’s Stakeholder Engagement component.
One of the most important stakeholder groups to consider is a group that may have little direct contact with the data governance body: parents and other family members. Data governance bodies must understand the legal implications of any data proposed to be included in the ECIDS to ensure that parents of children receiving education, health, developmental, and related services know, understand, and, where required, provide consent to disclosure of information that EC programs collect about them and their children. Under many federal laws, parents of children must also receive a privacy notice, which includes an explanation of the purpose of the data collections, and what data are shared or linked with other programs or agencies. State data governance bodies should support EC programs and service providers in addressing parents’ questions and concerns regarding how their family’s information will be used, who will have access to their family’s information and for what purpose(s), parents’ and children’s rights to privacy, when parental consent is required under the applicable laws, how programs will protect parents’ and children’s Personally Identifiable Information (PII) or protected health information (PHI) under the specific applicable laws, and whether and how parents can opt out, if applicable, of sharing their child’s data with the ECIDS. Data governance bodies can offer support to programs in determining when parental consent is required to share PII and communicating with families in easy-to-understand language about the importance of data integration efforts, how data integration will improve services, and what measures are taken to protect PII.

Pennsylvania and Rhode Island are examples of two states that developed materials for parents about integrated data. Pennsylvania’s guide for parents describes the benefits of sharing IDEA Part C and IDEA Part B, Section 619 data, the types of data that are collected, and the privacy safeguards in place in order to provide parents with information so that they could provide the required prior written consent. Rhode Island’s materials for parents discuss how developmental screening data is collected, shared, and used, as well as how parents may opt out of allowing their child’s PII or data to be shared. There are several federally-funded and non-federal resources available to assist states and programs in communicating with families, as well as resources designed specifically for parents. For example:

- PTAC offers a Best Practices guide for how schools and districts should communicate with parents about data privacy;
- The HHS-funded project Building Capacity to Use Linked Data provides a guide to assist programs in discussing data with families; and
- The DaSy Center’s families’ webpage provides information and resources for families of young children who want to know more about early intervention and preschool special education data under the IDEA.

4. Ensure Data Ownership is Clearly Included in Vendor Contracts

Both states and local EC programs may choose to contract with data vendors to manage data and report service and outcome data to meet state and federal reporting requirements. While vendors can offer valuable data management and integration services, state as well as individual EC programs should carefully review vendor contracts to ensure that, among other things, the terms of such contracts reflect the fact that EC programs retain ownership of their own data and maintain the ability to easily pull reports from data systems to enable data integration and analysis. For more information on this issue, see the

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14 Under the Family Educational Rights and Privacy Act (FERPA) and IDEA, only parents (i.e., not “families”) are given the rights to access, and to consent to the disclosure of, Personally Identifiable Information (PII) from their children’s early intervention and education records. Under FERPA, these rights transfer to the student when the student turns 18 years of age or attends a postsecondary institution.
15 Applicable laws and regulations include, but are not limited to, FERPA, Parts B and C of the IDEA, the Health Insurance Portability and Accountability Act (HIPAA), and the Head Start Program Performance Standards. There are also other federal, state, local, and program-specific laws that may be relevant for protecting the privacy of children’s records.
16 States and individual EC programs should review contracts for legal sufficiency, with data ownership being one of the issues a legal team reviews.
5. Ensure Children’s and Parents’ Rights to Data Privacy

When developing an ECIDS, there are several stages when it is critical to understand compliance with applicable privacy laws and best practices. For example: 1) before becoming an ECIDS partner and contributing data to an established governance framework; and 2) when approving specific uses of integrated data from the ECIDS by authorized parties to determine what is permissible under applicable privacy laws. Appendix B: Data Privacy Laws and Regulations describes applicable laws and regulations that contain provisions to protect the privacy of individual-level records from EC programs and services. Applicable laws and regulations may include, but are not limited to, the Family Educational Rights and Privacy Act (FERPA), IDEA Parts B and C, the Health Insurance Portability and Accountability Act (HIPAA), and the Head Start Program Performance Standards. There are also other federal, state, local, and program-specific laws that may be relevant for protecting the privacy of children’s records.\(^{17}\)

When becoming an ECIDS partner, stakeholders should work with the data governance body to determine what information is needed in the ECIDS, how that information will flow between agencies and who potentially would have access to such information in order to assess which law(s) may apply and what criteria must be met in order to be in compliance with relevant federal and state privacy laws. The information needed in the ECIDS will depend on what state and local government officials, EC program directors, and researchers identify as key research questions. In some cases, multiple statutes may apply to one set of records. Each of these privacy laws and regulations (i.e., FERPA, the HIPAA Privacy Rule, the IDEA Parts B and C confidentiality regulations, and the Head Start confidentiality regulations) have separate exceptions or circumstances under which, for instance, individual-level early childhood data can be disclosed with prior written parental consent, and if these laws apply, an analysis must be conducted separately under each of the applicable laws to determine if the disclosure is permissible under an exception to the respective prior written parental consent requirements. When prior written parental consent is required, appropriate policies, safeguards, and forms must be developed and reviewed regularly to ensure compliance with privacy requirements. If disclosure is permitted without prior written parental consent, stakeholders in almost all cases must develop data sharing agreements (see PTAC’s Written Agreement Checklist or the DaSy Center’s Data Sharing Agreement Checklist). Under these data sharing agreements, the parties must identify the PII being disclosed, the parties to whom the disclosure will be made, the purposes of the disclosure, and all applicable privacy laws. Under these agreements, the users of PII or data must ensure that it is shared only with authorized entities for authorized purposes and adequately protected (i.e., not re-disclosed) and destroyed after the PII or data has been used for the purposes specified in the agreement.

When approving specific uses of integrated data, the ECIDS data governance body may pre-approve types of projects and analyses that are permissible uses of integrated data and must comply with all applicable privacy laws. The ECIDS data governance body should also develop a process to evaluate new project and analysis requests to use integrated data that fall outside of its pre-approved list of projects to ensure these requests comply with the applicable privacy laws. For information on developing processes around researchers’ access to data, see the National Forum on Education Statistics’ guides for state education agencies and local education agencies.

In many cases, the release of fully de-identified data to approved individuals is permissible since it is not considered a disclosure under specific laws such as FERPA. The de-identified data may be in the form of summary tables and charts or de-identified individual level records. Fully de-identified data require the

\(^{17}\) The Children’s Online Privacy Protection Rule (COPPA) is an example of a law that may apply. For more information, please visit: https://www.ftc.gov/tips-advice/business-center/privacy-and-security/children%27s-privacy.
removal of direct and indirect identifiers and may also require one or more disclosure avoidance techniques to ensure the data are not able to be linked to a specific child. Additional information on de-identified data can be found in PTAC’s Data De-identification guidance document and its FAQ on Disclosure avoidance, as well as a joint DaSy Center and PTAC document on data de-identification that is relevant for data from early childhood programs.

If the use of ECIDS data requires the release of records containing PII, then it must be a permissible disclosure under all applicable privacy laws. For example, if the data are protected under FERPA, the data may be disclosed without parental consent to an authorized representative of certain statutorily-specified entities such as state or local educational authorities to audit or evaluate a federally- or state-supported education program. Each request for access to integrated data must be evaluated under each of the applicable privacy laws such as FERPA, HIPAA Privacy Rule, the IDEA Parts B and C confidentiality regulations, and Head Start confidentiality regulations, to determine if the disclosure and intended use are permissible.

In certain cases, there may be value in using an ECIDS to improve direct services to children and families. In almost all instances, prior written parental consent may be required to share data with non-educational agencies or institutions under FERPA or non-participating agencies under IDEA. However, there are exceptions to the prior written parental consent requirements. For example, under a specific narrow exception to FERPA and IDEA, a caseworker in a child welfare agency responsible for a particular child may be able to access, through an ECIDS, individual-level education records for those specific foster children for whom the caseworker is responsible for addressing the education needs. Using ECIDS data at the individual-level is only permissible with prior written parental consent, or if the entity considering disclosing the data has the legal authority to disclose the data, without such prior written parental consent, to the person or entity requesting access to it for the requested purpose.

6. Ensure Data Security
An ECIDS must protect its data without unnecessarily limiting access to authorized users. Protecting data from corruption or unauthorized use or access is referred to as “data security.” Data breaches to an ECIDS would jeopardize the confidentiality of child, parent, and staff data. All data owners (e.g., programs) and users of the ECIDS (e.g., state-level staff) should be trained to protect data confidentiality and preserve system security. For more information on data security procedures see PTAC’s Security Best Practices toolkit.

7. Ensure Data Quality and Comparability across Data Systems
Data must be accurate to meaningfully inform decision-makers, but data quality can be especially challenging for an ECIDS because data included in an integrated data system consists of data collected for different programs with various data quality standards and various data definitions. ECIDS consist of data that local programs collect. Such programs are more likely to take the time to train staff and collect high-quality data if they use the data to inform their own decision-making. To that end, state agencies should provide technical assistance to local programs on data entry and data use and monitor local programs’ data collection and reporting processes.

To ensure that data elements can be compared across programs in a meaningful way, the data governance body can work with stakeholders to understand how program definitions vary and, where possible, work with the different programs to develop a common data dictionary. A data dictionary includes definitions and attributes of specific data elements. States should consider using data elements and definitions from ED’s Common Education Data Standards (CEDS) project as well as health data standards. Alaska provides an example of a state that used CEDS as it planned for its preschool through postsecondary and workforce data system.
In addition to providing high-quality data aligned across programs, an integrated data system must accurately match child records from across systems. When unique identifiers (UIDs) are not used consistently across programs and data systems, ECIDS staff must employ complex matching techniques to link individual child records. A more efficient and accurate way to integrate data is to develop a process of assigning protected UIDs to children, either at the time of birth or at the time of first contact with designated programs or services. The SLDS SST created an issue brief on this topic entitled UIDs Beyond K12.

8. Build Capacity to Analyze and Use Data
For an ECIDS to help stakeholders make data-informed decisions, states must have the technical capacity to analyze the data, analysts must develop reports that are meaningful for stakeholders, and states must work with stakeholders to engage with data and build their understanding of data reports. Interviews with ECIDS staff in Georgia and Pennsylvania highlight the importance of having staff capable of cleaning data as well as developing, running, and analyzing reports that will inform policy decisions at the state and local levels. Georgia also emphasized the importance of working closely with stakeholders who request reports to ensure that the requester understands the results as well as the limitations of the report. While analysts will need to work with stakeholders to address specific data requests, the data governance body can engage stakeholders in designing ready reports that answer policy-relevant questions. Specifically, the data governance body and analysts should share drafts of standard public reports with stakeholders and revise such reports based on their input to ensure data are appropriately introduced and user-friendly.

As mentioned in the previous section, a local program is more likely to collect high-quality data if that program uses data to inform its own decision-making. Therefore, state agencies should support efforts to build the capacity of local program administrators and directors to use their own data when making programmatic or policy decisions. For example, even before Minnesota began to integrate Head Start data into its ECIDS, the state worked with local Head Start grantees to build capacity to use their own data, and to export data from their data management system developed by a private vendor. State agencies can assist local programs as they interpret and use standard reports created with ECIDS data (i.e., reports informed by data beyond their own programs). Resources that may assist states and local jurisdictions in efforts to use data in a meaningful way include:

- The SLDS SST ECIDS Toolkit on Data Use’s overview of the data use process, which includes sections on planning, creating, and supporting;
- The DaSy Framework’s quality indicators for states to support data use; and
- The HHS-funded project Building Capacity to Use Linked Data, which provides a Data Linking Planning Guide designed to help local EC programs and TA partners assess their capacity to engage in data linking efforts and identify next steps to accomplish data linking goals.

9. Build On and Leverage Other Data Integration Efforts
When developing or enhancing their own ECIDS, states can capitalize on lessons learned from recent ECIDS efforts in other states as well as other data integration and interoperability efforts in the education and health fields. For example, states may be able to leverage opportunities HHS offers through the...
Affordable Care Act. States also can utilize the lessons learned through ED’s SLDS grant program and the U.S. Department of Agriculture’s (USDA’s) National School Lunch Program (NSLP).

States may streamline and integrate health data systems to enable accurate determination of eligibility and enrollment for Medicaid, the Children’s Health Insurance Program (CHIP), premium tax credits, and cost sharing benefits through the state-operated health care exchanges set up to meet requirements of the Affordable Care Act. Because other federally-funded human services programs can benefit from systems enhancements to create a modern infrastructure for determining eligibility across programs, the government provided a time-limited exception to the cost allocation requirements for this work, set forth in Office of Management and Budget (OMB) Circular A-87 (Section C.3). The cost allocation exception provides states the opportunity to integrate eligibility determination functions across both health and human services programs, thus maximizing efficiency by allowing human services programs such as TANF, CCDF, and SNAP to utilize systems designed for determining a person’s eligibility for health coverage without sharing in the common system development cost as long as those costs would have been incurred to develop health systems. Medicaid and CHIP can pay for those common system functionalities with an enhanced federal match of 90 percent, subject to allowable costs as defined in these regulations. For more information on this cost sharing opportunity and other federal resources to support ECIDS, see Appendix A: Federal Resources to Support Data Integration. Pennsylvania used this 90-10 match opportunity to link its IDEA Part C payments and claims processing data to its Medicaid system to help maximize use of funds under its IDEA Part C system of payments, as described in the state profile section of this report.

The Department of Education’s SLDS SST has developed a number of Best Practice Briefs, which include briefs on topics such as working with a central state IT agency, data governance, and vendor engagement. States can also use existing tools developed by the education or health data systems when building or expanding an ECIDS. For example, states may be able to use the same Universal ID software that school districts use when creating UIDs for EC programs. North Carolina took this approach when assigning UIDs for Head Start participants.

USDA’s NSLP is another example where integration of data across systems can make a positive difference in providing services to children. The USDA is currently engaged in pilot programs in seven states where Medicaid agencies use their data systems to identify children who receive Medicaid and also meet NSLP household income standards. This information is matched with school enrollment records to identify and automatically certify eligible children for free and reduced price school meals, thus eliminating the burden of requiring low-income families to apply for these benefits. Sharing the Medicaid eligibility data across programs can increase access to nutritious meals every school day for thousands of children, while, at the same time, improving certification accuracy in the NSLP and reducing the paperwork burden on families and schools. Appendix C: Data Sharing Opportunities from USDA’s Food and Nutrition Service contains additional information on the pilot program, as well as information on using mapping tools.

10. Integrate and Link Broad Types of Early Childhood Data Together

While states have made strides in linking some early childhood data to their SLDS, most states do not yet have a functional ECIDS that can answer pressing policy questions concerning participation in various types of EC programs. By linking broad types of data together, states can gain a more complete picture of the EC services children receive. While this report focuses on integrating and linking EC data together, linking EC data to K–12 data may facilitate understanding longer-term outcomes of EC programs.
Although 32 states linked their K–12 data to some of their early childhood data in 2015, only nine states linked Head Start data to K–12 data, and 12 states linked subsidized child care data to other EC data. In 2015, nine states linked IDEA Part C and Part B, Section 619 preschool data with K–12 data, and six states linked these IDEA data to other early childhood data.

One way to link EC data to K–12 data is to integrate EC program data into an ECIDS, and then, in turn, link the ECIDS to an SLDS. All of the states profiled in this report are working towards linking data from their ECIDS to their state’s SLDS. Many other states are also working to bring together early childhood data to better organize and improve the use of existing data. To make ECIDS more useful, states should consider integrating and linking a broad set of relevant EC data, including some of the following types of data that may not yet be included in their ECIDS:

- Head Start data;
- Child care data;
- Data on early intervention and preschool services under IDEA Part C and Part B, Section 619;
- Public health and screening data;
- Homelessness data; and
- ECE workforce data.

Head Start Data

Head Start is a primarily federally-funded program that provides early education, health, mental health, family engagement, and other associated services to low-income children ages birth to five and their families. During the 2014–15 program year, approximately 1,600 Head Start grantees provided services to over one million children and families. Despite being one of the largest federal investments in early childhood education for low-income children ($8.6 billion in FY 2015), Head Start still serves less than half of the nation’s eligible population. An ECIDS that includes Head Start data allows states to have a more complete picture of the children being served and the various EC programs serving them, as well as potential gaps in service.

Despite the importance of incorporating Head Start data into ECIDS, many states still struggle with this task. There are several possible reasons for this, such as: 1) some stakeholders may have concerns that Head Start data might be used inappropriately in research analyses, particularly in comparing the developmental trajectories of children who participate in Head Start with those in other EC settings without accounting for differences in the populations served; 2) Head Start grantees may not be informed about how participation in the data system will directly benefit their program, staff, or participating families; 3) Head Start funds flow directly from the federal government to local grantees, and therefore, states do not collect or report data on Head Start programs that operate in their states; and 4) there can be a substantial cost burden associated with integrating data, both for the state and the local programs. Many states and local programs, however, have made progress in this area.

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The new Head Start Program Performance Standards, released by HHS' Office of Head Start in September 2016, require Head Start program coordination with state education data systems, including SLDS and ECIDS, through the integration and sharing of relevant data, to the extent practicable, if the program can receive similar support and benefits as other participating early childhood programs. States will still need to work closely with Head Start grantees to develop data sharing agreements that comply with the applicable privacy laws and demonstrate the benefits of participation for Head Start programs as they work to integrate Head Start data into their ECIDS. The new standards will provide more opportunities for these efforts.

While state policymakers may be most interested in the service and gaps analysis and other research results that ECIDS can yield, local Head Start programs may be more likely to agree to share data with an ECIDS if they understand the benefits of participation, if their concerns are addressed, and if the state can provide technical assistance. For example, local programs may be excited to share data if they know that, through participation in the ECIDS, they will receive information on how, in the aggregate, children served in their program are doing as they move to kindergarten and beyond. Programs may also appreciate capacity building opportunities to create data linkages and use integrated data in their own planning and evaluation processes. By providing information to local Head Start programs, an ECIDS can support their efforts to continuously improve services and link children and families to needed services while in the program, or as they transition to kindergarten. States that have successfully integrated Head Start data into their ECIDS through stakeholder engagement and carefully developed data sharing agreements, such as North Carolina, Georgia, and Minnesota, provide learning opportunities for other states thinking through their approach to data integration.

The Building Capacity to Use Linked Early Childhood Data project, funded by HHS, was created to help early care and education programs, including Head Start, and their state and community partners, in their efforts to use linked administrative data for program improvement and research purposes. It provides several short, easy-to-read resources to help program leaders as they work to use linked data to improve the quality of services for young children and families. These resources may also be useful for state leaders as they engage Head Start and other EC program partners in state ECIDS efforts.

### Child Care Data

From birth through kindergarten entry, children are in a variety of child care environments ranging from homes to centers to schools. Most center-based care, such as private day care centers or other community- or school-based preschool settings, is typically licensed and regulated. Data from these settings may be collected by states through child care licensing or subsidy agencies or school districts. However, many family child care providers or less formal, home-based care provided by family, friends or neighbors may be license-exempt. Licensing standards vary across states, although generally providers must be licensed when they care for four or more children. Data from license-exempt programs outside the subsidy system may or may not be collected by states. Over seven million children from birth...
to age five are served by nearly four million home-based providers, and most infants and toddlers are in family child care or home-based care. Therefore, when possible, including information on these settings in an ECIDS could significantly improve understanding of the full landscape of child care services in a given state, especially for the youngest children.

The newly reauthorized Child Care and Development Block Grant Act of 2014 requires states to monitor all child care providers that receive federal subsidies through the CCDF program. States collect data from all licensed child care providers, as well as data from the providers, children and families participating in the CCDF program. However, these data are often collected through different electronic systems and by different agencies or offices. Many states also collect data on the early learning workforce, tracking the credentials and professional development of those who care for children in child care or other EC settings, but their workforce systems do not always connect workforce data back to the settings where EC providers work. While 29 states have a QRIS (an accountability system designed to improve the quality of child care by defining quality standards, providing incentives and supports for program improvement, and making quality transparent to providers and parents), quality information from the QRIS has not often been linked to the CCDF subsidy data, licensing data, or workforce data systems used to answer questions of interest such as, What is the quality of the child care settings families are accessing with CCDF subsidies? However, some states have made progress in this area, and states will be required under the new rules to report quality information for all CCDF providers. Those states that have already made these linkages have a better understanding of the range of EC settings where children are served in early childhood, and are, therefore, more capable of answering questions of interest to state leaders and researchers.

Another challenge to collecting child care data is that many state child care data systems are outdated and underfunded. In fact, states are facing significant challenges as they work to expand their capacity to implement the requirements of the reauthorized Child Care and Development Block Grant Act. States can, however, use CCDF funding to support IT expenditures to improve the quality of child care in their state, and these costs are exempt from the five percent cap on CCDF administrative expenditures. In addition, states can work together on common data system development efforts or build on systems developed by other states. The SLDS SST created a webinar and brief on how states can coordinate their QRIS and ECIDS to increase capacity to address policy and programmatic questions.

Data on Early Intervention and Preschool Services under IDEA Part C and Part B, Section 619

IDEA Part C provides funds (almost $460 million in FY 2016) to states to ensure that appropriate early intervention services are provided to infants and toddlers with disabilities ages birth through two and their families and, at the option of the state, under a written policy adopted by the state, until the child enters kindergarten. IDEA Part B, Section 619 provides funds (almost $370 million in FY 2016) to states for the provision of special education and related services to children with disabilities ages three through five. During the 2014-15 school year, these two programs served 1.1 million young children with disabilities.

Pennsylvania links its IDEA Part C and Part B, Section 619 data with K–12 data, other early childhood data, and workforce data. To learn about Pennsylvania's process, read its Profile on Integrating Data on Children with Disabilities.

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Some young children with disabilities who receive IDEA services also participate in child care, Head Start, or state-funded preschool programs and receive IDEA services in these locations. Therefore, it is important to integrate IDEA Part C and Part B, Section 619 data with other EC program data to support more high-quality inclusive opportunities for children with disabilities as well as to better understand: 1) the full range of services that children with disabilities receive; 2) the EC programs that children with disabilities participate in; and 3) how various services and programs may relate to child outcomes. Additionally, it is important that states be able to connect data from IDEA Part C with Part B in order to have a more comprehensive picture of how many children receive IDEA services through their first five years. The DaSy Center compiled a list of Critical Questions that statewide data systems could answer if data on children with disabilities were integrated. Questions include examining what other services children with disabilities receive, what other EC programs children with disabilities participate in, and the quality of the program and services (as measured by state QRIS and staff qualifications associated with child outcomes).

While an integrated data system offers great potential for policy-makers to improve service delivery and outcomes for children with disabilities, there are multiple challenges to fully integrating IDEA Part C and Part B, Section 619 data with other data sources at the state level, or as part of an ECIDS. Challenges include providing unique identification numbers, ensuring compliance with IDEA Part C and Part B confidentiality provisions, as well as other applicable privacy laws, and creating data governance procedures that protect data use, security, and privacy throughout the period that PII is collected, maintained, or used. There are fewer data sharing challenges if the State Education Agency administers both the IDEA Part C and Part B programs through LEAs. States continue to make progress in overcoming these challenges. The DaSy Center’s State of the States found that, as of 2015, 16 states linked their IDEA Part C and Part B, Section 619 data together; nine states linked IDEA Part C and Part B, Section 619 data with K–12 data; six states linked IDEA Part C and Part B, Section 619 data to other early childhood data; and 11 states linked these IDEA data to workforce data.

Public Health and Screening Data
Research indicates that children’s mental and physical health status during the first five years of life impact early learning and school readiness outcomes, as well as later academic and life outcomes. Healthy development across all domains — including cognitive, language, social emotional, physical, and health — sets a strong foundation for children to continue to learn and grow once they move into elementary school.

Despite the important interplay between health and early learning during the first five years of life, health and early learning programs and services are often located in different state agencies, provide services and activities in different contexts, and operate under different funding mechanisms. While these systems provide different primary services (e.g., screening, immunizing, and treating health needs of young children vs. supporting the development of children’s cognitive, language, and social skills), both share a similar vision and strive to support children’s optimal growth and development so they can meet their full potential in school and beyond.

Utah is working to integrate health data with data from its EC programs. To learn about Utah's process, read its Profile on Integrating Public Health Data.

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If key health\textsuperscript{23} and early learning data are securely integrated, states can better understand the collective impact of coordinated health and early learning investments on children’s short- and long-term outcomes. Promoting cross-agency data sharing, alignment, and integration across state health and early learning data systems at the state level can also support efforts to coordinate and expand services across health and early learning sectors and potentially enable better-targeted and higher-quality services and referrals, minimizing duplication of services. For example, although developmental screening can be performed in a variety of settings (e.g., early learning programs, primary care, with home visitors), these providers do not typically have unified databases or repositories where they can enter or store such information. With data integration, providers can see whether a child may have been recently screened or whether they are already receiving needed services as follow-up to screening information. Some states and communities have created innovative collaborations to manage referral activities between medical homes and early childhood programs, using linked data.

Additionally, virtually all children come into contact with the health system in early childhood. States have detailed systems that document birth records as well as other key health information such as newborn hearing screenings. Some states use unique identifiers that are linked to birth records and aligned across systems to support data interoperability efforts. This alignment can help state programs that serve the same populations come together with shared vocabulary and purpose to examine not only how children and families are benefiting from an array of services designed to promote early childhood development but also where there might be room for improvement.

**Early Childhood Homelessness Data**

Young children are disproportionately represented in the homeless population. Recent data from a 2015 study of homeless families indicate that among persons who seek shelter because they are homeless in the United States, children are most likely to experience homelessness as infants in the first year of life.\textsuperscript{24} In addition, approximately half of children in U.S. Department of Housing and Urban Development (HUD)-funded emergency and transitional housing in 2014 were under age six.\textsuperscript{25} Research has demonstrated that homelessness during pregnancy and in the early years is harmful to a child’s development.\textsuperscript{26} Given the far-ranging consequences of early childhood homelessness and its prevalence, policymakers, early childhood programs, public schools, and housing providers must find ways to collaborate to support children affected by homelessness.

Collecting, sharing, and integrating data on early childhood homelessness across programs and systems can help communities collaborate and understand the scope of the problem locally, target housing and early care and education supports to reach families in need, and track progress towards preventing and

\textsuperscript{23} In this document, “health data” includes, but is not limited to: vital records, immunizations, results of developmental screenings, data from home visiting programs, Medicaid or other health insurance status, and information on participation in Women, Infants, and Children (WIC), TANF, and SNAP programs.


ending early childhood homelessness. Both early care and education programs (e.g., Head Start, Education for Homeless Children and Youth program) and housing programs (including the homelessness point-in-time count) collect data on early childhood homelessness and can contribute information about how to best serve young children. In addition, all LEAs have McKinney-Vento requirements for data collection that can inform community assessment of the needs of young children experiencing homelessness. Programs can align data and utilize common definitions and measures to support coordinated analysis and strategies to meet the needs of young children at risk for and experiencing homelessness. ED, HUD, and HHS recently released a joint policy statement on early childhood homelessness that includes specific recommendation for data sharing where feasible for states and communities.

**Early Childhood Workforce Data**

The importance of early childhood educators and caregivers in the lives of children and families is well-documented, and understanding the experiences, strengths, and challenges facing the ECE workforce can inform policy and program activities. Integrated data on the early childhood workforce can provide critical information that can help to identify opportunities for professional development and support for those who care for our youngest children.

However, most states do not currently have the capacity to fully integrate EC workforce data across EC settings. In part, the inability of states to fully integrate this data is because workforce data collection occurs differently across programs and states, and data are not often coordinated across programs within states. In addition, data may only be available in aggregate form at the state-level, and, in many cases data collections are voluntary or not well-funded.

It is important to consider the diversity of the workforce when connecting data on the workforce to an ECIDS or for other data integration efforts, as one data source may only hold a segment of the early childhood workforce. EC workforce data is commonly collected for state pre-K–12 teacher professional licensing and certification systems, state child care licensing systems, QRIS, professional development or scholarship programs, and voluntary workforce registries. These individual data collections may not align in the data elements they capture, and there may be gaps or overlap in data collected. For example, the pre-K–12 teacher licensing system may not include information on paraprofessionals or assistant teachers or caregivers, but some information about these critical members of the ECE workforce might exist in a separate workforce registry or other professional development data systems. More detailed information about the benefits, challenges, and efforts to integrate EC workforce data can be found in the report, *Early Childhood Workforce Data: Collection Practices and Possibilities*.

**Conclusion**

Integrated early childhood data allows states to better understand the full scope of services children receive in early childhood, learn what combinations of services are associated with positive outcomes for children, and identify service gaps. While HHS and ED acknowledge that integrating early childhood data is difficult, the Departments offer a variety of technical assistance and other resources to assist states in this work. Using this federal assistance, states have made tremendous progress in integrating early childhood data, including building and using ECIDS and linking those systems with SLDS and other data. As exemplified by the states profiled in this report, states across the country are working hard to expand data integration efforts, yet there is much work still to be done. HHS and ED encourage states to utilize
federal, state, and other resources to continue data integration efforts and to use these data to answer key questions about programs and associated child outcomes, improve program quality, and ensure that our nation’s youngest learners are more prepared to reach their full potential.
State Profiles
Each of the following state profiles describes the processes undertaken, challenges faced, and key lessons learned as states worked to develop, enhance, or use their ECIDS. These examples may benefit states as they aim to further integrate early childhood data.

Minnesota’s Engagement of Stakeholders in the Development of its Early Childhood Longitudinal Data System
In February of 2016, Minnesota’s Early Childhood Longitudinal Data System (ECLDS) went “live” with data from the Minnesota Departments of Health, Human Services, and Education. Specific data currently contained in their ECLDS include birth records, child care and early education participation, Kindergarten Entry Assessments, K–12 enrollment and assessment data, early childhood special education child and family outcomes for children receiving services under IDEA, QRIS data, TANF, SNAP, and teaching licensing. The system is housed in MN.IT, Minnesota’s central IT agency. Although the system only recently went live, Minnesota began its systematic stakeholder engagement strategy in 2014. Minnesota realized that to communicate effectively about and to sustain its ECLDS, it needed the support of active users and data owners. Stakeholders needed to understand the ECLDS operations, including data security protections. Data security is particularly important, as Minnesota has a culture of data privacy policies and has strong data privacy laws. Because the ECLDS contains data on children, it was essential that stakeholders understand the ways in which data are kept safe. In short, Minnesota needed the input of stakeholders to understand their needs, build awareness, and inform communication planning.

Minnesota’s systematic engagement process
As it began developing its ECLDS, Minnesota took specific steps to connect with stakeholders and ensure two-way communication. First, Minnesota asked its two governance groups (Research & Data Committee and Governing Body) to complete a systematic “stakeholder identification analysis” process. The Research & Data Committee and Governing Body groups constitute the governance structure of the ECLDS project. Members of the Governing Body are representatives from participating state agencies and professional associations representing the practice communities for health, human services, and education. The Governing Body is the decision-making entity for ECLDS governance. The Governing Body appoints members to the Research & Data Committee, who are knowledgeable about data, policy, practice, and child development. The duties of the Research & Data Committee are to make recommendations to the Governing Body to support the construction, enhancement, and longevity of the ECLDS.

As part of the stakeholder identification process, the governance groups identified individuals and organizations that had: (a) influence (e.g., advocacy groups that may support the ECLDS); (b) importance (e.g., parents); or (c) both influence and importance for the ECLDS work (e.g., agency leaders and service partners). Note that influence and importance were not always positive. That is, communication needed to also take into account the perspectives of critics. Minnesota chose to engage initially with stakeholders in group (c). Through focus groups comprised of influential and important stakeholders, Minnesota discussed the development process and sought advice on how best to communicate about the ECLDS to the public. The advice on communication was essential as different segments of the public have differing concerns and interests that must be taken into account when creating clear messages about the ECLDS and its purpose. Given the need to assure the public of the extensive privacy protections in place, the stakeholders provided key insights that influenced Minnesota’s messages and site release strategy. Minnesota used RTT-ELC funds to pay for facilitators for the focus groups. This group of stakeholders included representatives from state agencies (e.g., Health, Public Health Nursing, and Human
Services), service partners (e.g., Head Start, center- and home-based child care, and pediatricians), and advocates (e.g., Children’s Defense Fund of Minnesota and child welfare organizations). Minnesota engaged with stakeholders in groups (a) and (b) as needed during the website’s development and release process.

In addition to providing invaluable information regarding communication, the stakeholders reviewed and commented on existing policy questions and provided feedback on site features they desired. As the data sharing agreements prohibit sharing of individual data, the ECLDS can answer questions at the county or school district-level. Stakeholders knew that they would not be able to receive data about their particular program participants (e.g., What are the K–3 outcomes for children from Head Start Center A?), so it was very important that stakeholders agreed to the types of information that would be helpful to know at an aggregate level. Minnesota’s policy questions cover topics on participation (e.g., by demographics and intensity), quality (e.g., QRIS ratings and staff qualifications), and outcomes (e.g., K–3 outcomes by mix of service receipt). Stakeholders expressed an interest in having the capability to compare views of data (e.g., comparing different districts, or one district’s data to the state data) and to have a downloadable feature of analytics created for use in grant applications and reports. Stakeholders also suggested the site include descriptions of EC programs, as some users may not know the differences between EC programs. All of these features have been implemented on the ECLDS site.

Challenges and lessons learned
Minnesota’s main challenge with engaging stakeholders was time – stakeholders are busy and it is challenging to have them come in person to focus group or website testing sessions. To address this challenge, Minnesota conducted focus groups in the evenings in local communities to minimize travel. Minnesota also struggled to ensure that all stakeholders understood the relevance of the ECLDS for their own work and needs. Initially, some stakeholders misunderstood what the ECLDS would be able to do for them. For instance, some thought that the system would allow them to retrieve information on individual children, but data sharing agreements require that all information be reported from the ECLDS in aggregate form. Minnesota had to clearly explain to these stakeholders that data on their children and families are still represented in the ECLDS, and that the ECLDS will be useful for them as new features and functions are added to allow them to filter data in different ways and track children over time. Some stakeholders were initially concerned that the ECLDS was “another system” into which they had to enter child-level data. For these stakeholders, the state emphasized that the ECLDS takes advantage of preexisting data and does not represent more work for ECE staff.

For other States interested in thoughtfully engaging stakeholders, Minnesota suggested including the considerations of groups and individuals who are not proponents of ECLDS in the stakeholder analysis. It is helpful to be aware of what critics of these data systems may say and use this to inform communication plans and messages tailored to specific groups such as school-based programs, legislators, state agency partners, and the general public. Additionally, Minnesota suggested undertaking the stakeholder identification analysis every one or two years to ensure that new stakeholders are involved appropriately. Finally, Minnesota noted the importance of valuing and being willing to adapt plans based on stakeholder input.
Georgia’s Use of Data from Their Cross Agency Child Data System

Since 2011, Georgia’s Cross Agency Child Data System (CACDS) – housed at Bright from the Start: Department of Early Care and Learning (DECAL) – has integrated data on children from birth to age five and the programs and providers who serve them. To allow children to be matched across programs, the system provides each child with a unique ID. CACDS includes data from Early Head Start and Head Start, Child and Parent Services (CAPS), Quality Rated (Georgia’s QRIS), Georgia’s Pre-K attendance data, IDEA Part C and Part B, Section 619, home visiting, and links to Georgia’s P–20 and Workforce system. The de-identified child-level data in CACDS is securely stored and also includes provider-level data.

Georgia’s engagement with stakeholders to develop policy and research questions
Beginning in 2011, and evolving through 2016, DECAL worked with participating agencies (e.g., Department of Public Health and the Department of Education) to develop a list of reports and research questions that would be helpful for policymakers. Stakeholders were most interested in reports of unduplicated counts of participation across various combinations of early childhood programs; participation rates, by disability and child care subsidy status; and outcome measures for children who had previously participated in various combinations of early childhood programs. In the future, CACDS reports will be able to examine how different subgroups of children fared on third grade reading assessments based on different variables, such as child race/ethnicity, or the quality rating of the child’s preschool, as determined by Georgia’s QRIS.

While these reports sound straightforward, DECAL must work closely with stakeholders to address detailed report requirements prior to their development. For example, if a requester is interested in whether children who participated in Head Start reach future grades on time, DECAL would work to determine the timeframe of interest, such as how many days of Head Start would count as “participating,” and whether the requester was interested in disaggregating by Head Start site or grantee. Before generating the report, DECAL would also want to address limitations of the report. Once the requester agreed to report specifications, DECAL would run the report and include specifications discussed to ensure all readers understood the nuance of the report. Future reports could be generated with the same specifications.

Challenges and lessons learned
Georgia has learned it is important to take the necessary time to explain to stakeholders the types of questions that CACDS can answer and the caveats that come along with those answers. It is important the requester agrees to the report’s data specifications and that the report is what the requester expected to receive. Additionally, due to the cross-section of program data and nuance of the data processing, it is unlikely that a casual user could appropriately analyze the data without support from the DECAL CACDS data team. Most program researchers understand their own program’s data elements and definitions but not another agency’s data elements and definitions. For example, the data field “service types” at the Georgia Department of Public Health is referred to as “environments” at the Georgia Department of Education. CACDS has helped to standardize data elements across agencies, but CACDS staff still need to assist program researchers and policy analysts in understanding how the data elements link across agencies. Georgia has learned that it is essential to have state staff with the appropriate expertise available to assist with CACDS data requests.
North Carolina’s Progress Integrating Head Start Data into NC ECIDS

Since 2013, North Carolina has made significant progress to incorporate data from North Carolina Head Start grantees into their state early childhood data system, known as the North Carolina Early Childhood Integrated Data System (NC ECIDS). NC ECIDS includes data from NC Pre-K, Subsidized Child Care Assistance, IDEA Part C and Part B, Section 619, TANF, and SNAP. North Carolina has several policy questions it intends to answer with its ECIDS, including: 1) How many children and families are participating in early childhood programs and services and what are participants’ demographic characteristics?; 2) How many children are being served by multiple programs (e.g., Head Start, TANF, and SNAP)?; 3) What is the quality of various early childhood programs in North Carolina, and is it changing over time?; and 4) What are the characteristics of the ECE workforce in North Carolina? North Carolina will be able to answer the last two questions once ECE workforce, regulatory, and licensing data are linked to the NC ECIDS.

North Carolina’s process for the integration of Head Start data
To begin the lengthy process of integrating Head Start data, the NC ECIDS staff and the North Carolina Head Start State Collaboration Office (NC HSSCO) Director examined which vendors the Head Start grantees in their state were using to manage their data, and discovered that, similar to other states, 52 of the 56 grantees were using the same data vendor. The NC HSSCO Director worked with the larger grantees in the state to reach out to the vendor and let the vendor know of their interest in working with the state to share their data. The NC ECIDS staff and the HSSCO Director then had several discussions with the vendor about options for integrating the data and ultimately decided on an annual data export of a specific set of data elements which will be sent to the NC ECIDS for integration. The vendor and state signed a contract, agreeing to tasks required to complete the data export. The Head Start data will be stored at the North Carolina Department of Information Technology (NC DIT), and children will be assigned UIDs in order to link the Head Start data with data in other systems. NC ECIDS leveraged existing state resources by using the same software that is used to assign UIDs to children in North Carolina public schools. Currently, NC ECIDS staff is working with the vendor to begin the process of exporting the Head Start data to NC DIT. For the four Head Start grantees that do not use the same vendor, North Carolina plans to work with them to perform their own data export once a year to NC DIT.

The Head Start data vendor and North Carolina agreed on a fee for an export of one year’s worth of Head Start data. The fee includes the tasks necessary to prepare and export the data. North Carolina is using funds from their RTT-ELC grant to support this work. However, costs are projected to be higher for subsequent years of data exports; therefore, North Carolina plans to integrate one year of Head Start data and then continue negotiating with the vendor to reduce ongoing costs.

North Carolina’s engagement of the Head Start community
North Carolina engaged with the Head Start community very early in the process of data integration. They reached out to each grantee to explain NC ECIDS and why it is important for Head Start data to be integrated into this system. For instance, the NC ECIDS team highlighted that Head Start is a key part of the EC delivery system in North Carolina, and by integrating Head Start data into NC ECIDS, Head Start agencies would be able to better understand the other EC services their children receive. Additionally, if NC ECIDS is connected to North Carolina’s P–20W data system (School Works), it will be able to answer critical policy and research questions, such as the long-term outcomes for children that participated in Head Start and in other early care and education programs. Other outreach efforts included webcasts, presentations at statewide meetings, and close collaboration with the Director of the NC HSSCO. North Carolina found the collaboration with the NC HSSCO Director to be particularly crucial for working with the Head Start grantees, as the grantees already had an
existing and trusting relationship with the Director. The Director emphasized the importance of being part of NC ECIDS, explained the data integration process, and responded to any Head Start grantee concerns. The Director continued to engage the grantees throughout the process, and was transparent about the work being undertaken to develop the NC ECIDS.

North Carolina created a memorandum of agreement (MOA) between the Head Start grantees, the vendor, and NC DIT, which authorizes Head Start data to be exported from the data vendor to NC DIT. As of July 2016, 46 of the 52 Head Start grantees that use the same data vendor had signed the MOA. Under the advisement of the NC HSSCO Director, the NC ECIDS team also gathered active consent for all Head Start children and families to participate in the data system. The NC HSSCO Director created a consent form for programs to use with families. The data vendor will train HS grantees on how to flag children whose parents did not consent to have their child’s data shared with NC ECIDS.

Challenges encountered and lessons learned
North Carolina has cited engagement with the Head Start data vendor as one of their biggest challenges in their work developing NC ECIDS. North Carolina worked extensively with the vendor to understand the different Head Start data elements, to decide what information was necessary to facilitate data integration, and to find a process for integrating the data that satisfied both parties. Throughout this process, North Carolina offered various alternatives to the vendor and leveraged information they learned from other states facing similar challenges.

For other states interested in incorporating Head Start data into their ECIDS, North Carolina highlighted the following lessons: 1) be flexible and open to multiple possible ways to proceed with data integration efforts; 2) seek out and learn from the work of other states that have made progress in this area; 3) engage the Head Start community early in the process, especially to help them understand the benefits of participation in a state system, both for the state and for the grantees themselves; and 4) promote transparency throughout the entire process and be open to answering any questions that arise, in order to continue building trust and strong relationships between the various key players.

Next steps for NC ECIDS
The NC ECIDS team expects to receive the exported Head Start data in November 2016. They anticipate that these data will be integrated with NC ECIDS by early 2017. North Carolina also plans to integrate ECE workforce, regulatory, and licensing data and link its ECIDS to its SLDS.

Additionally, North Carolina is engaging with researchers to understand the research questions they would like to ask and how NC ECIDS data can help answer those questions. The research community is particularly interested in longitudinal outcomes for children that participate in North Carolina early childhood programs, including how program characteristics and children’s demographics are associated with outcomes. Researchers will be able to request de-identified individual-level data from the state.
Minnesota’s Progress Integrating Head Start Data into their ECIDS

Minnesota’s interest in integrating Head Start data

In Minnesota, the Head Start community is very interested in understanding patterns of progress for children participating in the program. The Minnesota Head Start Association (MHSA) has published several reports summarizing the progress children make during their time in Head Start. However, questions about how children fare after they leave the program and enter elementary school are a bit more difficult to answer. As such, Minnesota recognized the need to integrate Head Start data into their ECLDS and link to Minnesota’s K–12 data system. After data from multiple EC programs and services are fully integrated, Minnesota hopes to answer policy questions about: 1) how many children are participating in each public EC program and family support program, and what is the unduplicated count of children participating across all programs in Minnesota; 2) which EC settings children attend; 3) the quality of these EC settings; 4) the intensity and duration of each service children receive; and 5) children’s progress and outcomes from birth through third grade. In addition, partners in state agencies administering TANF, SNAP, and Child Care Assistance in Minnesota are interested in linking data with Head Start in order to examine which families are receiving multiple services and where there may be service gaps.

Minnesota’s engagement of the Head Start community

From the beginning of the process, Minnesota chose to include key Head Start stakeholders in their ECLDS governance structure, including the Executive Director of the MHSA and the director of a local Head Start agency. Minnesota also kept stakeholders informed through briefings at meetings of the MHSA and on-going statewide research projects, as well as meetings of the Minnesota data vendor Users Group, which meets three times a year and is comprised of state staff and Head Start agency staff responsible for data entry.

The process for integrating Head Start data in Minnesota

Beginning in 2010, facilitated by the MHSA, several Head Start grantees in Minnesota began participating in data aggregation and analysis to examine benchmarks and annual trends and to inform instruction. Minnesota developed data sharing agreements for all grantees that agreed to share their data with the state.

Currently, 19 of 33 Head Start grantees participate in these data activities. Therefore, when the Head Start programs began conversations with the state about integration of their data into the ECLDS, the programs already had a structure in place for retrieving data from their data systems. Minnesota worked closely with the Head Start data vendor used by most grantees in the state to strategize how to integrate Head Start data without incurring substantial costs. After discussions with the vendor, Minnesota was able to create a report format that would allow Head Start agencies to export their data in a standard way, and then share the necessary Head Start data elements by submitting it to the State through a secure online portal. Three Head Start grantees are currently using the new system to share data into the ECLDS. Minnesota continues to meet with Head Start directors to discuss pilot outcomes and the benefits of participation.

Minnesota also found it very helpful to have IT staff as part of the ECLDS team who could talk directly to the data vendor programmers. For example, the ECLDS IT staff and data vendor held meetings to discuss the data fields to map between the systems so that variable names and definitions would align across systems. This coordination helped the data vendor resolve issues in a more efficient manner.

Like other states, Minnesota also set aside some of its RTT-ELC funds to support school districts and Head Start agencies in updating software and receiving training on the software to meet RTT-ELC reporting requirements. Software upgrades included new Head Start data vendor software.
Challenges and lessons learned

Minnesota cites the assignment of UIDs as one of their biggest challenges in this work, particularly across Head Start programs and school districts. Developing close working relationships between Head Start programs and local school districts was instrumental for working through this challenge. The State is currently testing a new method for assigning UIDs to streamline this process.

Because Head Start agencies are regional entities, individual agencies may opt in or out of the system. This optional participation results in some Head Start children not being represented inside the ECLDS. Therefore, Minnesota has cautioned that the ECLDS data cannot yet fully inform statewide policy decisions around Head Start.

Minnesota stresses that the participation of Head Start stakeholders in their ECIDS governance structure from the beginning of the process was crucial to the success of their efforts. Engagement allowed the Head Start community to have a voice in the process, see how governance worked, and inform the state of their own interests as the system developed. In particular, the Head Start stakeholders wanted individual Head Start grantees to receive aggregate information on their children’s elementary school academic outcomes after completion of Head Start. Head Start grantees will also receive children’s UIDs to allow them to work with their local school districts to conduct local evaluations.

As described above, Minnesota was able to develop a unique way to work with Head Start grantees and the Head Start data vendor in their State to extract and upload data while minimizing costs. While Minnesota highlights this as a successful effort, the state also points out that it may be a bigger challenge for other states if their Head Start grantees are not used to downloading data from their vendor on a regular basis. In such situations, the grantees would likely require support from state-level offices, such as the State Head Start Association or State Head Start Collaboration Office. Grantee staff may also require additional training on how to enter data, standardize data definitions across interested agencies, and conduct data exports from the vendor software.

Next steps for the integration of Head Start data in Minnesota

At the time of this publication, three Head Start grantees in Minnesota are participating in the ECLDS. Minnesota hopes that the benefits received by these “early adopters” will encourage other Head Start grantees in the state to pursue data sharing efforts. Minnesota will be able to include Head Start data as one of the data sources in their ECLDS in the fall of 2016, though it will be from this limited number of Head Start grantees. Minnesota will continue to support this work with grant funding from their ED SLDS grant, which continues through 2019.
Maryland’s Work to Integrate Child Care Data into their ECIDS

Maryland’s development of a child care data system and its integration with other early childhood data

Currently, Maryland has a comprehensive child care data system that it is revamping to enable more efficient program administration. For the purposes of research and internal analysis, data from the child care data system has been linked with the state’s kindergarten readiness assessment system (KRA), which collects individual-level information about the state’s kindergartners, including family demographics, type of care received before kindergarten (e.g., Head Start, child care, state-funded preschool, special education), and kindergarten readiness status in seven areas of development. The KRA is also linked through individual UIDs to the SLDS with K–12 data to allow for evaluation of how each child’s level of readiness at kindergarten relates to subsequent academic performance.

Maryland’s Child Care Administrative Tracking System (CCATS) was developed and fully implemented in 2007. CCATS integrates administrative records from child care licensing, subsidy, professional development, and QRIS ratings into one integrated system. The state has benefited from this system, enabling electronic administrative and program management, internal analysis, tracking of data throughout the year, streamlined reporting to funders and state officials, as well as research through their Research Advisory Group. For example, the state is able to analyze the quality of child care facilities, how many children are in accredited centers, and the education levels of teachers or providers. Maryland can run standardized reports as well as analyze data to determine answers to specific questions about the quality of programs that provide care to children receiving child care subsidy services, the qualifications of providers and teachers in facilities that receive child care subsidies, or other questions of interest to stakeholders.

Maryland’s RTT-ELC grant funds enabled further development of CCATS, including the development of the Enrollment Attendance Reporting System (EARS) which will enable child care providers and parents to submit enrollment and attendance information electronically. Families and child care providers will be able to interface with the system through a portal that feeds information into the EARS and CCATS systems. Child care facilities will have the option to upload enrollment and attendance information for all children, including those receiving subsidies, link teachers with the child in the classroom, generate staffing reports and child rosters, and submit electronically for child care subsidy reimbursements. Parents will be able to apply for child care subsidies and programs will be able to verify eligibility, enrollment, and attendance online, reducing burden on families and freeing up time for program staff to focus on other activities.

Challenges and lessons learned

Like many state child care data systems, Maryland’s legacy system was initially developed in the 1990s and was primarily used for internal tracking and management. When building out the new CCATS system, the EARS system was envisioned as a way for providers and parents to gain restricted access to information and provide information to the CCATS system directly. During the development of the public-facing EARS system, the state engaged with several child care providers to test the system and gather feedback on the usefulness of the EARS portal. In response to feedback from providers, Maryland made adjustments to the system to better meet the needs of end-users. Working in phases, Maryland is first rolling out the provider and family portals that will allow for child care subsidy enrollment, attendance monitoring, and reimbursement functions. Then, Maryland will expand the system to allow for providers to verify licensing, credentialing, and training online. Gathering input from child care providers, staff, and families has greatly contributed to the development of a user-friendly system. In their effort to engage families in this process, the state has relied on child care providers to reach parents. The state experienced significant challenges in engaging family child care providers in testing the portal’s functionality and would recommend
that states consider specific strategies to involve these important end-users.

The Maryland team recommends bringing together stakeholders early in the development process to think about what the system should look like and what it should be able to do. After a decision is made about the ideal functionality, the state can then work to build the technology to fit the scope of community needs. In addition, states should think carefully about data as they develop websites and public-facing portals for providers and families to use. Strong firewalls must be in place to ensure that users can access their own information but not original data tables or other restricted data.
Pennsylvania’s Integration of IDEA Part C and Part B, Section 619 Data

In Pennsylvania, key stakeholders at the state level were very interested in creating a seamless birth through five system for young children receiving early childhood services, including those children receiving IDEA services (Part C and Part B, Section 619). Therefore, in 2007, the Pennsylvania Departments of Public Human Services (DHS) and Education (PDE) began collecting data on their early learning programs in a single management information system called PELICAN (Pennsylvania’s Enterprise to Link Information for Children Across Networks). PELICAN is composed of six systems, including: 1) child care provider certification; 2) subsidized child care; 3) QRIS; 4) state preschool and Head Start; 5) the Early Learning Network; and 6) the Early Intervention case management system, which houses IDEA Part C and Part B, Section 619 data on child evaluations, individualized education programs (IEPs) or individualized family service plans (IFSPs), service coordination, and payments/claims processing (for Part C only). This profile focuses on Pennsylvania’s efforts to link together their Part C and Part B, Section 619 data, as well as integrate these data with other early childhood programs and services data, and, ultimately, to other program data to obtain longer-term outcome information.

Pennsylvania’s process for the integration of Part C and Part B, Section 619 data

In 2008, PDE and DHS reached out to IDEA Part C and Part B, Section 619 stakeholders, such as leadership from the local early intervention and preschool special education programs, parents, and members of the State Interagency Coordinating Council (SICC). PDE, DHS, and the stakeholders discussed integrating the separate systems into the Early Intervention case management system. The case management system promoted a seamless birth through five system for children receiving IDEA services and allowed Pennsylvania to explore policy questions such as the following: Does entering into IDEA services earlier and receiving more years of service make a difference in terms of child outcomes? The case management system is administered through DHS and funded in part by PDE.

As a result of the stakeholder discussion, the PELICAN Early Learning Network assigns two common identifiers to each child participating in certain programs administered by the Office of Child Development and Early Learning (OCDEL) or enrolled at specified providers participating in an OCDEL program. One of the assigned unique identifiers links to other DHS systems, and one links to PDE. The combined system allows the program providers to enter certain data (e.g., demographic data) into the system just once, as opposed to requiring providers to enter identical data into a new system when a child transitions from IDEA Part C to Part B, Section 619. However, while the technology of the system allows for a single entry of most data, providers must still obtain parental consent to use HIPAA- and FERPA-protected data (e.g., public insurance information) collected under IDEA Part C for Part B, Section 619. Parents can choose to opt out of the information sharing process. To encourage parents to consent to the sharing of data between Part C; Part B, Section 619; and the Early Learning Network, the OCDEL created a guide for parents that describes the benefits of sharing data, the types of data that are collected, privacy safeguards, and the types of outcome data that PELICAN stores, including social emotional skills, acquisition of knowledge and skills, and use of appropriate behaviors to meet needs.

27 The Early Learning Network is a data repository for information about children participating in all state-funded Head Start and preschool programs and some private early learning programs. A link also exists to children participating in the early intervention and preschool special education programs.

28 OCDEL supports families and their children, from prenatal through school age, by using data, research, and stakeholder guidance to support the provision of high-quality services. Its mission is to provide families with access to high-quality services to prepare children for school and life success.
Pennsylvania’s use of the integrated IDEA data

The collective PELICAN systems were designed to be a seamless data system that can answer questions about the services received by children from birth to grade three as well as children’s outcomes. For instance, the state can determine whether children who received early intervention or preschool special education services are also enrolled in subsidized child care services. In addition, Pennsylvania can examine the quality of the child care programs in which children with disabilities were enrolled, provided they were enrolled in a program that voluntarily participates in the state’s QRIS. PELICAN also links to Pennsylvania’s K–12 SLDS, which was partially funded by an SLDS grant from the U.S. Department of Education. These linked systems allow Pennsylvania to explore questions about longer-term outcomes for young children who receive IDEA services. For example, Pennsylvania is currently examining whether receiving more years of early intervention and/or preschool special education is associated with improved child outcomes in third grade. Further, the state is examining how the quality of child care (using data from the QRIS) is associated with child outcomes in elementary school, such as third grade state assessments.

Challenges and lessons learned

Pennsylvania’s main challenge with integrating and using IDEA Part C and Part B, Section 619 data centers on staff capacity. Staff need specialized knowledge and training to develop, run, and analyze reports in order for the PELICAN data to inform policy and program decisions. Staff also need training and time to ensure that common identifiers are properly assigned and that data integrity is routinely evaluated. When Pennsylvania first began the process for integrating early intervention and preschool special education data, the local providers were initially very hesitant to integrate their systems. Through combined leadership meetings between the local Part C coordinators and the local Part B, Section 619 coordinators that occur six times a year, a common sense of working together in a birth through five Early Intervention system has emerged. This has led to increased cooperation at the local interagency coordinating councils.

For other states interested in integrating IDEA Part C and IDEA Part B, Section 619 data into an ECIDS, Pennsylvania suggested engaging stakeholders early to understand their needs and informing them of how integrated data could help meet those needs. Pennsylvania also suggested using novel funding sources to support work on integrated data. Pennsylvania received a 90-10 match from HHS to link the IDEA Part C payments/claims processing data to its Medicaid system.

Next steps for Pennsylvania’s data integration efforts

Pennsylvania worked closely with IDEA Part C and IDEA Part B, Section 619 local leadership, representatives from various early intervention and preschool special education professional associations, and the SICC, and Pennsylvania is now considering working more closely with parents to understand the types of data they would like to be able to access from the case management system. Parents cannot currently access the Early Intervention data system, but the state is considering creating a tool for parents to be able to access the system and retrieve information. Pennsylvania would also like to help facilitate a more interactive exchange between the early intervention and preschool special education providers and families, to help break down barriers and encourage greater family involvement. Additionally, DHS and PDE are considering whether they should look at outcome measures other than third grade test scores as a “benchmark” of the efficacy of participation in early learning programs. The state is currently convening groups of researchers to consider those and other such measures.
Utah’s Efforts to Link Health Data with Early Learning Data in their ECIDS

Utah’s interest in integrating health data to inform research and policy
When Early Childhood Utah, a program of Utah’s Department of Health (DOH), first began to develop their ECIDS, they were interested in gaining a comprehensive picture of all of the services children and families receive in Utah that relate to early health and development. With their ECIDS, they hoped to examine long-term outcomes for children who participated in various EC programs and improve the quality of programs through the use of data to inform decision-making. In particular, they were very interested in tracking children’s health outcomes, in addition to early learning outcomes. Five broad policy questions drove their efforts, including: 1) Are children from birth to age five on track to succeed when they enter school?; 2) Which children and families are participating in which programs and services?; 3) What characteristics of programs are associated with positive outcomes for children?; 4) What are the education and economic returns on early childhood investments?; and 5) How is data being used now and how could it be used in the future to inform policy and resource decisions?

Early Childhood Utah’s process for integrating health and early learning data
Early Childhood Utah’s efforts to develop an ECIDS began in the fall of 2011 within the DOH. Start-up funding came from an Early Childhood Comprehensive Systems grant, and Early Childhood Utah will seek additional funding to maintain and enhance the Early Childhood Integrated data system. The ECIDS system is designed for research purposes only; it will contain de-identified data on children from birth to age five who are served by participating agencies and programs. Utah’s ECIDS does not store source system personal identifiers or identifiable demographic information (e.g., full addresses, full dates of birth) to protect the privacy of the children. Early Childhood Utah began the process of data integration with outreach and collaboration to potential partners, the establishment of a data governance structure, and the development of data sharing agreements.

Over the course of several years, the DOH developed Master Person Indices (MPIs). The MPIs integrate data from several source systems to identify a distinct child and match that child with all early childhood services that the child has received. Children are then assigned an ECIDS specific UID so that it is not necessary to list source system identifiers associated with the child, such as a social security number, within the ECIDS database.

Since Early Childhood Utah is a program of the DOH, it will initially include data from EC public programs (e.g., Early Intervention Part C, Home visiting), state registries, commercial health insurance payers, government payers, and health data sources. The Early Childhood Utah team has reached out to partners outside of the DOH to develop data sharing agreements. As of August 2016, Early Childhood Utah was in the process of exploring, negotiating, or actively integrating data from the following external data sources: Child Care subsidy, Ages and Stages Questionnaire (ASQ) online, Help Me Grow Utah, and Early Head Start/Head Start programs.

Early Childhood Utah looks ahead to the integration of internal data sources such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Home Visiting funded by MIECHV and IDEA Part C.

In the future, Early Childhood Utah also plans to explore the possibility of incorporating data from TANF, SNAP, and the Low Income Home Energy Assistance Program (LIHEAP), as well as data on children with special health care needs and children in foster care (from Utah’s Division of Child and Family Services).

Early Childhood Utah has established a research committee that will serve as the gateway for all data requests from the ECIDS. The research committee is made up of representatives from each source of data included in the system (e.g., Head Start, IDEA Part C, Help Me Grow, WIC), and at least two independent researchers. All requests to access data from the ECIDS for research purposes must have approval from the committee and the Institutional Review Board.
(IRB) of the requester’s institution. Any representative on the research committee that is uncomfortable with a proposed research project can veto the use of their data for that specific project.

Challenges and lessons learned
Utah’s DOH is a “hybrid entity” under HIPAA, which means that only parts of the DOH are covered by the HIPAA Privacy and Security Rules. For example, its Medicaid program is a covered entity, but its public health programs are not. Utah has successfully integrated health data from sources that are not covered by HIPAA into their MPI (and eventually into their ECIDS). However, health data that are covered by HIPAA present a challenge for integration into the ECIDS. The Early Childhood Utah team operates as a public health project, which would probably qualify as a valid exception to the use and disclosure prohibitions of the HIPAA Privacy Rule, permitting a covered entity to share its data with the ECIDS. Nevertheless, the ECIDS is having trouble obtaining HIPAA-protected data at this time. The team is exploring the possibility of integrating such data in the future.

Utah had originally planned to utilize a single infrastructure to pull together demographic data necessary to uniquely identify a child from data sources. This has turned out to be a challenge as EC-related information comes from entities that are covered under various privacy rules (e.g., HIPAA, FERPA, and IDEA). Utah found it unclear how such rules apply to data that end up in a single system that uses identifiable demographic data to uniquely identify a child.

For other states interested in integrating data that is not protected by FERPA, the Early Childhood Utah team points out that it is important to determine early on which health data are protected by the HIPAA Privacy Rule and which are not, as the integration of HIPAA-protected data may take more effort. Additionally, when considering programs for possible data integration, it is important to assess the program’s data quality and determine which acts, laws, or regulations govern the steps for appropriate disclosure of the program’s data.

Early Childhood Utah also stresses the importance of written documentation that clearly outlines procedures and steps taken throughout the process of building an ECIDS. State agencies may experience high turnover, and it is important to preserve this cultural and institutional knowledge. Developing strong, trusting relationships and a transparent process is vital for building an integrated data system. These relationships are critical to engaging all of the necessary stakeholders, as well as talking through and alleviating any concerns stakeholders might have about sharing data with the state.

Next steps and future goals for Utah’s data integration efforts
In the future, Early Childhood Utah intends to establish the ability to query Utah’s K–12 data system. Through this query, Utah’s ECIDS will be able to match identities between the two systems. This will facilitate research based early childhood program evaluation. This integration with the K–12 data system will be an important next step for Early Childhood Utah, given their strong interest in comparing, in aggregate, developmental outcomes for children who participated in the state’s various early learning programs.
Rhode Island’s Efforts to Link Universal Screening Data to its ECIDS and SLDS

Rhode Island’s interest in linking screening data

The Rhode Island Department of Education’s (RIDE) 2015–20 Strategic Plan for Education includes a goal of increasing early childhood developmental screening rates for children aged three through five. This goal builds on previous work by RIDE to meet IDEA’s Child Find Obligation. Specific questions that Rhode Island hopes to address by linking screening data for children from birth through five provided through KIDSNET (described below) with data from its Early Care and Education Data System (ECEDS) and SLDS data include the following: 1) What are the demographics of children who do and do not receive screenings?; 2) Were children who failed a screening referred for further evaluation and did they ultimately receive appropriate services?; 3) For children who failed a screening, but were not referred for an evaluation, did they eventually need special education services and, if so, at what age?; and 4) Were children who received special education services ready for kindergarten, as measured by state and district assessments? Rhode Island worked to create a statewide system for its screening data and has the capacity to answer the first and second questions now and will be able to answer the third and fourth questions in the coming years.

Rhode Island’s KIDSNET data system

Since 1997, the Rhode Island Department of Health (RIDOH) has maintained an integrated child health information system, called KIDSNET, for maternal and child health programs that includes data on screening, vital records, immunizations, WIC, and IDEA Part C. Children are initially entered into KIDSNET at birth when they receive their first immunization in the state or when they receive another public health service (e.g., WIC, IDEA early intervention, home visiting, or lead screening). As soon as a child is added to KIDSNET, he or she receives a KIDSNET ID. RIDE is automatically notified of the new child and their KIDSNET ID and creates a State Assigned Student ID (SASID) that will be used in both the ECEDS and the SLDS. KIDSNET data can then be linked to ECEDS and SLDS data by KIDSNET ID. By the end of 2016, Rhode Island expects to link its screening data for children birth to five years of age and other health data (e.g., lead levels, immunizations, hearing assessments, and home visiting) to ECEDS, which, in turn, will link KIDSNET data to the SLDS.

While KIDSNET is the custodian of health information, the data owners, or program managers, determine who can access their program’s data. Parents are informed about data collection, data sharing, and data use several times and may “opt out” of allowing their data to be shared. Rhode Island has developed information for parents of newborn babies and parents of children not born in the state. Much of the data relevant to the birth to age three population can be shared under HIPAA and Rhode Island state laws. Signed consent to share individual data is required by some programs such as WIC and IDEA Part C. School districts — which must comply with FERPA and IDEA — are required to obtain signed consent to share the Child Outreach Screening data for children aged three to five. In addition, RIDE has a data sharing agreement with the RIDOH to share KIDSNET data. RIDE created individual data sharing agreements with other state agencies rather than a global agreement, as legal restrictions vary by agency and individual legal review proved to be more expeditious.

Rhode Island’s process to ensure universal screening and linking screening data

Rhode Island screens all children at birth as part of its universal newborn screen. This screening helps identify common risk factors for poor developmental outcomes (e.g., low maternal education). Based on the screening and identified risks, children may be referred directly to IDEA Part C or to Rhode Island’s risk assessment and response home visiting services. Developmental screening using validated screening tools is required at specified ages from nine months to 30 months. Primary care physicians (PCPs) screen children according to the state’s Early and Periodic Screening, Diagnosis and Treatment (EPSDT) schedule, which mirrors the Bright Futures recommendations for health supervision of infants and young children. Many PCPs in
Rhode Island utilize an electronic screening system to administer and score developmental screens. The screening results are electronically sent to KIDSNET.

Developmental screenings for children aged three to five are conducted by local school systems. Rhode Island’s Child Outreach Screening goals include locating and screening all children each year between the ages of three and five prior to kindergarten; ensuring that children who red-flag on screenings (i.e., fail the screening) are referred for an evaluation and, if eligible, receive the necessary special education services; and that screening procedures are followed with fidelity. Before 2014, school districts had inconsistent screening and referral procedures, lacked collaboration with PCPs and community-based programs, and could not easily locate children who were not yet enrolled in early care and education programs. In addition, RIDE could not easily monitor screening for children aged three to five without a centralized repository for screening data. Rhode Island used RTT-ELC funds to build a statewide system that collected Child Outreach data in KIDSNET and allows RIDE to access statewide Child Outreach screening data to inform policy decisions.

By collecting the Child Outreach data in KIDSNET, school districts can find and screen children living in their district who they were formerly unable to locate, monitor which children are being referred for an evaluation and which children receive special education services, and share the Child Outreach screening and referral data with other districts when children relocate. Using KIDSNET also enables school districts to share screening results with individual PCPs and allows PCPs to request screenings for patients who have not yet been screened and about whom they are concerned. Specifically, parents need to provide consent to the screening, to share results with their child’s identified PCP, and to share results with the child’s identified early childhood teacher. While a child’s identified PCP may view the Child Outreach data in KIDSNET, early childhood teachers cannot yet access Child Outreach data in KIDSNET and, instead, receive a hard copy of the results.

Challenges and lessons learned
Rhode Island acknowledges that the federal privacy laws posed some challenges to data sharing and staff received guidance from ED’s PTAC and DaSy TA Centers about how to adhere to FERPA and IDEA regarding confidentiality and parental consent. For states that are considering linking screening data to an ECEDS, Rhode Island recommends careful consideration of HIPAA, FERPA, and IDEA at the beginning of the planning process.

Next steps
By the end of 2016, Rhode Island expects that screening data will be linked to its ECEDS and, through ECEDS, to the SLDS. Rhode Island is working to expand the group of authorized individuals who have access to screening data in KIDSNET to include Head Start programs. Rhode Island is also working to develop additional capacity within KIDSNET which will allow them to answer additional policy questions statewide and by local jurisdiction.
Oregon’s Development of a Registry for the Early Care and Education Workforce

Oregon developed the first iteration of its ECE Workforce Registry in the late 1990s, as part of a long-term plan to develop a comprehensive career development system. Initially, participation in the registry was voluntary for child care providers in Oregon. However, after an extensive planning and roll-out process, Oregon greatly expanded its registry to include all of the ECE workers in the state’s licensed facilities. This effort was led by the Oregon Early Learning Division’s Office of Child Care (OCC) and the Oregon Center for Career Development in Childhood Care and Education (OCCD) at Portland State University.

With their expanded Workforce Registry, Oregon plans to answer questions such as: 1) How many individuals are there in the ECE workforce in Oregon, and what are their demographics?; 2) What is the education level of the ECE workforce?; 3) What kind of training and professional development does the ECE workforce receive?; 4) What additional training is needed, and which ECE providers could use additional support?; 5) Which types of individuals are staying in the ECE field; and 6) Where should Oregon invest its money to continue to support the ECE workforce?

Oregon’s process for developing their comprehensive Workforce Registry

Between 2009 and 2011, Oregon carefully planned the expansion of its Workforce Registry with the goal of creating a more comprehensive database that could inform policy decisions. Oregon also wanted the expanded registry to support frontline ECE workers and those supporting the workforce, such as licensing specialists and TA providers. Recognizing the importance of gathering input from multiple stakeholders, Oregon established several groups to help guide the project, including a steering committee with representatives from different key agencies, including the OCCD, the Head Start Collaboration Office, the Child Care Resource and Referral network (CCR&R), the Department of Human Services, and the OCC. Other planning workgroups included representatives from the research community, funding agencies and foundations, licensing and training agencies, and other professional organizations. Representatives from Oregon’s CCR&R gathered input from EC providers on the functionality they would like in a more comprehensive registry. A research partnership group also provided input on what ECE workforce data researchers would like to help answer research questions.

After gathering all of this input, the OCC and the OCCD worked collaboratively to establish plans and a timeline that would guide the development of the database. They also examined existing policies of various agencies that administer relevant early childhood programs in Oregon to determine where changes might be needed in order to promote alignment across systems. For instance, at the time, Oregon’s existing (smaller) Workforce Registry had 10 core knowledge categories. OCCD staff would examine each training ECE workers completed and determine which category it would count toward. However, at the time, the OCC required that each staff person in a licensed facility have at least 15 hours of training, eight of which had to be in child development. The two agencies worked to reconcile these differences in training requirements and developed one standard set of expectations for the trainings that the ECE workforce should complete. After extensive planning and research, the team decided to build their new registry (as opposed to purchasing one), and hired programmers at Portland State University to carry out the work. The expanded registry rolled out in 2011. Prior to this date, the registry (which used to be only a voluntary career lattice) contained complete workforce data on approximately 4,400 ECE workers; by August 2016, the registry career lattice included data on about 14,604 workers. In addition, the registry verifies ongoing training documentation for approximately 22,000 designated positions working in licensed facilities. The work was mostly supported with CCDF and RTT-ELC funds.
Oregon’s Workforce Registry in action
When Oregon’s expanded Workforce Registry rolled out in 2011, it represented a large systems change for many individuals who work in the ECE field, including staff, providers, licensing specialists, and TA and training specialists. This initial rollout and implementation was a bit challenging for state staff and practitioners, as it presented ECE staff with a different way to submit their training and education documentation to meet licensing requirements. For instance, ECE staff working in licensed facilities used to submit their training documents and certificates to the OCCD only if they were applying for a step on the career lattice, otherwise they kept them on-site. The new registry changed the process for how licensing specialists conducted on-site licensing visits. As part of the rollout, the OCC conducted several visits and presentations across the state to help prepare the field.

Oregon reports that most of the ECE field now appreciates the enhanced Workforce Registry. It helps the state examine policy questions of interest and informs decisions, while also allowing ECE providers to enter the registry and retrieve information from their own individual accounts. Each year, Oregon creates an ECE workforce data report and state leadership and advisory groups use the information derived from the Workforce Registry to inform legislation requests, to hold conversations with private funders, and to plan for workforce supports that may be needed in the future.

How Oregon’s Workforce Registry interacts with and connects to other data in the state
Currently, Oregon’s Workforce Registry is linked to two other databases managed by Oregon’s Early Learning Division (ELD): the licensing database and the facilities database. The facilities database captures all information on EC facilities in the state. It also tracks information on criminal background checks and records licensing dates and licensing categories. The Workforce Registry and the ELD facilities database securely communicate data every night, and populate information into a facility’s staff qualification and training log. This way, Oregon is able to examine, for instance, both the education level of an ECE worker, as well as his or her tenure in the ECE field (in licensed facilities). Oregon can use this information to inform both licensing and training qualifications for individuals. Directors of EC programs can also use these data to assist with their licensing renewal process. Finally, Oregon’s QRIS staff can access data on the workforce to inform QRIS ratings. In the future, Oregon’s ELD hopes to build a more comprehensive database that will include all QRIS data and connect to the Workforce Registry.

Currently, the Workforce Registry is not connected to data on children and families in Oregon. However, OCCD and ELD staff, along with the research partnership group, have begun to examine data on the workforce and how this compares to U.S. Census data regarding children and families. For instance, they are exploring whether the demographic composition of the workforce (e.g., race, ethnicity) in various communities aligns with the demographics on eligible children and families that might be served in EC settings in those communities. This alignment (or lack thereof) could have implications for types of training that should be made available to the workforce in different communities. For example, the workforce may need trainings on cultural diversity or trainings offered in languages other than English. Oregon is also exploring whether workforce trainers reflect the cultures of the communities in which they are working. In the future, when the Workforce Registry is connected to Oregon’s SLDS, Oregon would like to study the associations between a child’s kindergarten entry assessment scores and the credentials of his or her caregivers.

Challenges and lessons learned
Oregon OCCD chose to create a database that includes all staff who work in licensed facilities. This inherently excludes providers working with children in unlicensed facilities. Oregon is developing strategies to include those unlicensed providers/facilities receiving subsidy dollars in the workforce database. Additionally, EC directors cannot currently see training documentation for their staff in real time. Oregon
is working to allow directors to access more timely information on their ECE workers.

For other states that are interested in or working to build a workforce database that integrates data from multiple systems, Oregon would highlight the importance of engaging all relevant stakeholders from the beginning of the process. Oregon especially stresses the importance of including frontline staff in the decision-making. Oregon also points out the importance of planning and allowing an ample amount of time for testing and piloting before a system is launched. Additionally, when Oregon rolled out their expanded registry, they did so across all licensing types, all facilities, and all licensing specialists. Oregon points out that it may be helpful to, instead, use a phased approach, such as beginning with a portion of the early learning provider population and then slowly expanding to include more provider types.
Appendix A: Federal Resources to Support Data Integration

This Appendix includes information on federal funding, TA centers, and toolkits and other resources to support data integration.

Federal Funding for Data Integration

Statewide Longitudinal Data Systems grant program

The Statewide Longitudinal Data Systems (SLDS) grant program, funded by ED, awards grants to states to design, develop, implement, expand, and use longitudinal data systems. In some states, these data systems span kindergarten through high school (K–12), while in others they span as far as preschool through the workforce (P–20W). These systems aim to enhance the ability of states to more efficiently and accurately manage, analyze, and use key education data. Information from these systems can inform decision-making for a wide variety of education stakeholders, including states, school districts, individual schools and educators, and early learning programs. Specifically, these systems can provide information to stakeholders regarding how children and youths are prepared for and transition from early care and education to K–12 education to college and the workforce. These systems can also facilitate the use of administrative data for education research and evaluation purposes. Currently, 31 grantee states are focused on building ECIDS and many of these states connect their ECIDS to their K–12 or P–20W data systems.

Early Childhood Comprehensive Systems (ECCS) grant program

The Health Resource and Services Administration (HRSA) within HHS awards the Early Childhood Comprehensive Systems: Building Health Through Integration grants to support the integration of services for young children birth to age three across the health, social services, and early education sectors, with the goal of improving services for children and families. Since 2007, grants have been awarded to states or other organizations that have experience building such systems. As of 2015, ECCS grantees operate in 47 state and the District of Columbia. In past competitions, grantees had to focus on one of the following three topical areas: 1) mitigating the effects of trauma during early childhood; 2) expanding developmental screening in early education settings; or 3) improving the quality of child care for infants and toddlers. Beginning in 2016, new grantees must focus on improving children’s health and developmental outcomes and family well-being through a Collaborative Innovation and Improvement Network (CoIIN) approach. Grantees must identify one to five place-based communities that will participate in the CoIIN within their state or territory. One important aspect of building more coordinated systems involves the integration of data across sectors, an activity which these funds can support.

Capitalizing on Investment in Health IT Systems to Integrate Human Services Data

In order to implement requirements of the Affordable Care Act, states have made significant investments in streamlined and integrated health data systems to enable accurate determination of eligibility and enrollment for Medicaid, CHIP, and premium tax credits and cost sharing benefits through state-operated health care exchanges. Because other federally-funded human services programs can benefit from systems enhancements to create a modern infrastructure for determining eligibility across programs, the government has provided a time-limited exception to the cost allocation requirements for this work, set forward in OMB Circular A-87 (Section C.3). The exception provides states the opportunity to integrate eligibility determination functions across both health and human services programs, thus maximizing efficiency and increasing access to health and human services systems to contribute to national health and wellness goals and address the social determinants of health. It allows human services programs —

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29 This count is based on the number of states that have been awarded funding through either the SLDS or RTT-ELC grant programs to focus on building ECIDS.
including, but not limited to, the TANF, the CCDF, and SNAP — to utilize systems designed for determining a person’s eligibility for health coverage programs without sharing in the common system development costs, so long as those costs would have been incurred anyway to develop systems for the health care exchanges. Medicaid and CHIP Medicaid can pay for those common system functionalities with an enhanced federal match of 90 percent, subject to allowable costs as defined in these regulations. However, human services programs do still have to pay for any of the development costs for functionality that is exclusive to their own needs.

For additional details on considerations for using the exception and suggested system functionalities that can be integrated, please refer to the January 23, 2012 Tri-Agency letter. This letter outlines how states requesting funding for integrated eligibility systems should follow the guidance of the Centers for Medicaid & Medicare Services (CMS)-issued expedited Advance Planning Document (APD) checklist — which summarizes federal requirements for planning and implementing activities — and submit their APD to CMS and the human services program offices that will eventually benefit from the system. For additional information on IT systems and data integration in the context of Medicaid, please refer to this website.

Federal Technical Assistance Centers to Support Data Integration

The SLDS State Support Team

ED’s SLDS State Support Team (SST) is composed of state data systems experts whose primary goal is to support states in their development and use of SLDS, including ECIDS. The SST assists states via webinars, workgroups, workshops, best-practices briefs, and on-site visits. Areas of assistance include, but are not limited to, data governance, stakeholder engagement, data use, project management, and sustainability. The SST also provides assistance in areas such as transparency, collaboration and linkage of data across state and local agencies, vendor management, strategic planning, and the development of data dictionaries. The types of support provided by the SST are based on states’ needs and evolve in response to current challenges in the field. Any state, regardless of federal grant status, is eligible to receive assistance from the SST. The SST also offers specific support for states that are building ECIDS. Notable resources and activities include:

- The Early Childhood Integrated Data Systems Toolkit, which covers seven components of developing an ECIDS: 1) purpose and vision; 2) planning and management; 3) stakeholder engagement; 4) data governance; 5) system design; 6) data use; and 7) sustainability.
- Videos that provide additional information on ECIDS, such as this video introduction that provides an overview on “What is an ECIDS,” including a definition and relevance for states to support early childhood initiatives. In addition, this video provides an overview of one of the key goals of ECIDS — having a distinct count of children served. The video demonstrates the need for and how to calculate the distinct count so resources and program decisions can be supported across the various programs serving children in their earliest years.
- “State Spotlights” highlighting how various states have developed and used their ECIDS. For instance, see this State Spotlight on North Carolina’s ECIDS.
- Webinars on topics related to integrating data and ECIDS such as this webinar that explains how states can coordinate across their ECIDS and QRIS.
- Issue briefs covering a variety of topics related to ECIDS such as this brief on Unique Identifiers: Beyond K–12, which discusses options and key considerations for uniquely identifying children prior to kindergarten entry.

The Center for IDEA Early Childhood Data Systems (DaSy)
The DaSy Center is a national TA center funded by the Office of Special Education Programs (OSEP) within ED. DaSy provides TA and resources to state agencies to build capacity in developing or enhancing data systems for IDEA Part C early intervention and IDEA Part B preschool special education.
programs, including support for incorporating IDEA data in the development of ECIDS. DaSy collaborates with other national projects to leverage current knowledge and generate new ideas and products to help state agencies create and expand early childhood cross-agency and longitudinal data systems that include the IDEA Part C and Part B preschool data required under IDEA. Highlights of relevant DaSy activities include:

- A final report from a needs assessment, *IDEA Part C and Part B Preschool State Data Systems: Current Status and Future Priorities*, which summarizes what was learned about the current status of IDEA Part C and Part B Section 619 data systems and progress that states had made to improve their data systems;
- Developing the national picture of IDEA Part C and Part B Preschool state data systems using online interactive *State of the States maps*;
- Developing and using the DaSy Data System Framework, which is intended to enhance the capacity of IDEA Part C and Part B Preschool state staff to understand state data systems so they can lead or actively participate in data system development efforts, use state data systems to comply with IDEA federal reporting requirements, and answer program and policy questions;
- Outlining the *Critical Questions About Early Intervention and Early Childhood Special Education* that states can use to examine their data systems and improve programs and services;
- Developing numerous resource documents on various topics including the role of IDEA Part C and Part B Preschool participation in designing and using linked or integrated early childhood data and data privacy in ECIDS; and
- Providing targeted and intensive TA for states on various topics including ECIDS, data privacy, enhancing data systems design, improving data quality, and securely linking key data between Part C and Part B Preschool.

**The Privacy Technical Assistance Center (PTAC)**

ED’s Privacy Technical Assistance Center (PTAC) provides the public with information about data privacy, confidentiality, and security practices related to student-level longitudinal data systems and other uses of student data. PTAC provides information through documents, training materials, and direct assistance. PTAC hosts an Early Childhood Data Privacy webpage with resources that pertain to children in EC programs, including preschool, Head Start, and child care. Highlights of relevant PTAC materials include:

- Cross-walk of *IDEA and FERPA* confidentiality provisions — compares requirements from the two laws around consent, inspection and review, retention and records, procedural safeguards, and dispute resolution;
- The *FERPA Exceptions-Summary* — includes information on audit and evaluation and school official exceptions; and
- The *Data Governance Checklist* — provides a checklist of best practices for state or local organizations that are establishing or maintaining a data governance program.

**Early Learning Challenge Technical Assistance**

The Early Learning Challenge Technical Assistance provides TA to support the successful implementation of RTT-ELC grantee state projects and provide cross-sector early learning resources to all states and territories. The center has created resources that assist all states in developing integrated data systems, including:

- Key Considerations for Data Systems that Support TQRIS (Tiered Quality Rating and Improvement Systems) — includes information on engaging stakeholders and functional considerations for a TQRIS data system; and
- Early Childhood Workforce Data: Collection Practices and Possibilities — co-authored with the SLDS SST, it includes information on the importance of high-quality workforce data and
identifies challenges and promising examples of RTT-ELC states’ efforts to integrate and coordinate workforce data collection.

Toolkits and Other Resources to Support Data Integration

The Common Education Data Standards Initiative
The Common Education Data Standards (CEDS) project, managed by ED, is a national, collaborative effort to develop voluntary data standards for a key set of education data elements to streamline the exchange, comparison, and understanding of data within and across P–20 institutions and sectors. There are early learning elements added from each of the key programs in early childhood (e.g., Head Start/Early Head Start, Child Care, Early Intervention, Early Childhood Special Education) from the federal, state, and local levels. Over 70 CEDS users have focused on the Early Learning domain. Alaska provides an example of a state that used CEDS as it planned for its preschool through postsecondary and workforce data system.

The INQUIRE Data Toolkit
The INQUIRE Data Toolkit, funded by the Office of Planning, Research and Evaluation in the Administration for Children and Families (ACF) within HHS, serves as a technical assistance resource for state and local programs to support the use of common data elements, building from the CEDS, when collecting and using data to address questions and inform decisions related to EC programs and services. The Toolkit includes a Dictionary of Common Data Elements that may be used in continuous program improvement efforts, program reporting, program evaluation, or program monitoring efforts. The dictionary provides a wealth of information about each data element, including any parallel efforts through CEDS. The Toolkit also includes a Linkages Guide, which offers examples of questions that states might find useful in their efforts to monitor, evaluate, and/or improve EC programs in their state. Each question outlines the needed data elements, provides possible analytic strategies, and links to the necessary data elements in the Dictionary of Common Data Elements.

The ACF Confidentiality Toolkit
The ACF Interoperability Initiative developed the ACF Confidentiality Toolkit to provide important guidance on how to protect sensitive information when engaging in information sharing or integration projects under ACF-funded programs. The Toolkit aims to support efforts at the state, local, and tribal levels to enhance coordination across service sectors, including through the integration of data. It explains applicable privacy and confidentiality laws and regulations for the following human services programs: child welfare, TANF, child support, child care, the Low-Income Home Energy Assistance Program (LIHEAP), and SNAP. The Toolkit also provides case study examples and includes sample data sharing agreements to jump start implementation efforts.

Child Care & Early Education Research Connections
ACF’s Office of Planning, Research and Evaluation (OPRE) funds the Child Care & Early Education Research Connections website to promote high-quality research and inform policy through free access to thousands of publications and datasets. The website includes resources related to linking and analyzing early childhood data and ensuring data confidentiality and security.

State Advisory Councils on Early Childhood Education and Care
The American Recovery and Reinvestment Act of 2009 (ARRA) funded the State Advisory Councils on Early Childhood Education and Care (SACs) grant for $100 million for a three-year grant period. States used SAC funds to assess the status of their early childhood education systems and develop recommendations to improve the system. One of the recommendations focused on unified data collection systems. The Final Report of the SACs included recommendations for how states can develop a unified data system and each state’s progress and need for a unified data system.
Appendix B: Data Privacy Laws and Regulations

*The Family Educational Rights and Privacy Act (FERPA)*

*FERPA* is a federal law that protects the privacy of student education records. The law applies directly to all educational institutions (i.e., schools) and educational agencies that receive federal funds under an applicable ED-administered program. Therefore, *FERPA* does not apply to data from all EC programs and services. For instance, data from Head Start programs are only subject to *FERPA* if the Head Start grantee is operated by an educational institution or agency (such as a school district; see further discussion of Head Start below).

Generally, *FERPA* requires that educational agencies and institutions obtain prior written consent from the parent in order for PII 30 from a student's education record to be disclosed. However, *FERPA* allows educational agencies and institutions to disclose PII from education records, without consent, under certain circumstances. The two most likely exceptions to the requirement of prior written parental consent that may apply in the ECIDS context are the audit and evaluation exception and school official exception. The audit and evaluation exception permits the disclosure of PII from education records to an authorized representative of a statutorily specified entity, 31 such as state and local educational authorities, if it is for the purpose of an audit or evaluation of a federal- or state-supported education program and if all other criteria to comply with the exception are met. The school official exception permits schools and LEAs to disclose PII from education records to a designated school official who has been determined by the school or LEA to have a legitimate educational interest in the information and who performs a function for which the school or LEA would otherwise use its own employees if all the other regulatory criteria to comply with the exception are met. 32 *FERPA* also contains re-disclosure and record keeping requirements that generally apply to any further disclosures of PII from education records by third parties and that would need to be met by a state educational authority or LEA that administers the ECIDS. 33 Additional information on these exceptions to consent can be found in PTAC’s *FERPA Exceptions – Summary*. *FERPA* also allows states to adopt more protective privacy provisions, so it is critical to understand relevant state laws designed to protect student privacy.

**Confidentiality Provisions under Parts B and C of the Individuals with Disabilities Education Act (IDEA)**

The confidentiality provisions in the *IDEA* Part B regulations apply to children with disabilities ages three through 21 under Part B of the *IDEA*. The confidentiality provisions in the *IDEA* Part C regulations apply to infants and toddlers with disabilities (from birth to age three or, at the State’s option, through age five if the state has adopted a policy to provide *IDEA* Part C services) and their families under Part C of the *IDEA*. These provisions protect the PII collected, maintained, or used under Part B and Part C of the *IDEA*, respectively. Generally, parental consent is required prior to disclosure of PII unless a specific narrowly-tailored exception applies. While the *IDEA* regulations incorporate many of the provisions of, and applicable exceptions under, *FERPA* regarding when parental consent may not be required prior to the disclosure of PII, there are some differences in how Parts B and C of the *IDEA* apply these exceptions. A separate analysis must be conducted under the applicable *IDEA* provisions in addition to an analysis under *FERPA* if both *IDEA* and *FERPA* apply. Most of the exceptions to the prior written consent requirement under both *IDEA* and *FERPA* are permissive, which means that educational agencies and institutions may, but are not required to, disclose PII. There are also separate exceptions under the *IDEA*.

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30 Examples of PII include, but are not limited to, a student’s name, date of birth, Social Security number, home address, and the type of disability that an identifiable student has. The term PII is defined in 34 CFR § 99.3.
31 20 U.S.C. §§ 1232g(b)(1)(C), (b)(3), and (b)(5)
32 See 34 CFR §§ 99.31(a)(1)(i)(B) and 99.31(a)(1)(ii) for additional information.
33 See 34 CFR §§ 99.32 and 99.33 for additional information.
For example, to ensure the continuity of services at age three from Part C to Part B of the IDEA, Part C early intervention providers may disclose very limited specific PII as part of a referral without parental consent subject to a state opt-out policy. Additional information can be found in ED’s guidance on IDEA and FERPA Confidentiality Provisions and Frequently Asked Questions on Understanding the Confidentiality Requirements Applicable to IDEA Early Childhood Programs.

The Health Insurance Portability and Accountability Act (HIPAA)

HIPAA’s Privacy Rule applies to covered entities, defined as health plans, health care clearinghouses, and health care providers that transmit health information in electronic form in connection with covered transactions (for example, billing insurance claims). However, under the HIPAA Privacy Rule’s definition of protected health information or PHI, in general, there is an exception for records covered by FERPA as being exempt from the definition of PHI in the HIPAA Privacy Rule. Some schools might meet the definition of “health care provider” under HIPAA, for example, when a school provides health care to students in the normal course of business, such as through its health clinic. But only if a provider of care also conducts any covered electronic transactions in connection with that health care, is it then a covered entity under HIPAA. In order for a school to be covered under the HIPAA Privacy Rule, it must not be covered by FERPA, it must be providing health care, and it must engage in covered transactions, such as billing insurance electronically. Early childhood programs do not always clearly fall under the school analysis and should review the applicable provisions in the HIPAA Privacy Rule and FERPA (and if applicable, Parts B and C of the IDEA) to determine whether the HIPAA Privacy Rule’s FERPA exception to the definition of PHI applies.

As a covered entity, such a school would be required to comply with the HIPAA standards for transmitting information with respect to its transactions, and with the HIPAA Privacy and Security Rules. Additional information can be found in the joint guidance document on the Application of FERPA and HIPAA to Student Health Records.

Protects for the Privacy of Child Records in the Head Start Program

Performance Standards

On September 1, 2016, the Office of Head Start published a final rule revising the Head Start Program Performance Standards (HSPPS) which apply to all Head Start grantees — Early Head Start, Head Start, Migrant and Seasonal Head Start, and American Indian and Alaska Native Head Start programs. The new standards include procedures for protecting personally identifiable information under Part 1303, Subpart C. There are two exceptions when this subpart would not apply described in Sec. 1303.21 for educational agencies or institutions subject to FERPA and records of children referred to, or found eligible for services under, IDEA. The IDEA Part B and C confidentiality regulations apply to children receiving IDEA services in Early Head Start and Head Start programs.

Similar to FERPA, programs are allowed to disclose PII from child records without parent consent under certain very narrow and specific exceptions. For the SLDS and ECIDS context, there is an exception in Sec. 1303.22(c)(2) which allows a program to disclose PII without consent to officials from a federal or state entity to evaluate education or child development programs, provided that some control is in place such as a written agreement. For the records of Head Start children who also receive services under either Part B or C of the IDEA, the program may need to obtain prior written parental consent to disclose PII to non-participating agencies that have access to PII through the SLDS or ECIDS.35

34 45 CFR Chapter XIII, RIN 0970-AC63
35 The definition of a participating agency is different under Part B and C of the IDEA, but generally includes agencies that collect, maintain, or use PII to implement the IDEA, but does not include primary referral sources or payer agencies.
Also worth noting is Sec. 1302.53(b)(3) which requires program coordination with state education data systems, including the SLDS and ECIDS, through the integration and sharing of relevant data, to the extent practicable, if the program can receive similar support and benefits as other participating early childhood programs.
Appendix C: Data Sharing Opportunities from USDA’s Food and Nutrition Service

USDA Food and Nutrition Service — Data Sharing to Give Children Automatic Access to Nutritious Meals at School

Direct certification is a method of identifying and certifying eligible children automatically for free school meals by matching student enrollment data from education agencies and eligibility data from other public assistance programs. This process improves student access to free nutritious meals at school, which can improve student wellness and the ability to learn. Children who are enrolled in public and non-public schools that participate in the USDA Food and Nutrition Service’s (FNS) National School Lunch and School Breakfast Programs are included in the match process with other public programs, regardless of age, including young children in pre-school programs and kindergarten. This process helps ensure children’s access to nutritious meals throughout the school day. Since 2004, the Richard B. Russell National School Lunch Act (NSLA) has contained provisions requiring local school districts to conduct direct certification using data from the Supplemental Nutrition Assistance Program. The NSLA also allows school districts to conduct direct certification with the TANF, the Food Distribution Program on Indian Reservations, and with certain other specific populations (i.e., children who are migrants, homeless, in Head Start, and in foster care).

Since SY 2012–2013, FNS has used legislative and administrative authority to conduct limited demonstrations to evaluate the use of Medicaid data to directly certify children for free school meals. Initial evaluations of the early demonstration data indicated that direct certification with Medicaid can increase the number of directly-certified students. For example, New York City’s experience the first year was a 7.1 percent increase in the number of students directly certified for free school meals. The evaluation also estimated that including direct certification for reduced price school meals (which had not been done previously) had the potential to increase the percentage of students directly certified by approximately 2 percent.

To further leverage the potential program benefits in direct certification with Medicaid, in January 2016, FNS invited state agencies to apply to participate in a new demonstration that will use Medicaid data to test direct certification for both free and reduced price meals. This will be the first time that FNS will pilot direct certification for reduced price meals. Seven states were approved to participate in the demonstration beginning school year 2016–2017 — California, Florida, Massachusetts, Nebraska, Utah, Virginia, and West Virginia. Combined, these states serve over seven million children who are certified for free and reduced price meals. If these states were to experience similar increases as New York City in directly certifying eligible students for free meals and also meet the projected 2 percent increase in direct certification due to reduced price, the demonstrations could result in up to a 9 percent increase in directly-certified students, a significant number of whom were not receiving free or reduced price meals previously. States will have additional opportunities to conduct the demonstrations in future years, with the goal of up to 20 states participating by school year 2018–2019. This new demonstration has the potential to significantly benefit thousands of children across participating states.

USDA Food and Nutrition Service — Mapping Tools to Build Capacity to Feed Children During Summer Months

The USDA Summer Meal Programs offer nutritious meals and snacks to low-income children during the summer months and long vacations from school. Often, these children receive meals through the School Breakfast Program (SBP) or the National School Lunch Program (NSLP) during the school year, and may be at risk of hunger or poor nutrition during the summer months. FNS, with the help of community partners, has built several online mapping tools to give easy access to data concerning summer meals.
These tools layer data from multiple sources to display information that can help state agencies and high poverty communities all over the nation build capacity to serve nutritious meals and help families locate and access the meals for their children. Getting healthy meals during the summer months and vacations from school can make a significant difference in a child’s well-being and ability to learn. Some of the available online mapping tools include:

- The Capacity Builder Tool (http://www.fns.usda.gov/capacitybuilder) allows communities to identify areas of need and gaps in Summer Food Service Program meal service and to identify potential partners to fill those gaps. The mapping tool only requires internet access; experience or access to Geographic Information System (GIS) software is not necessary. Childhood hunger can be plotted on a map using either the percentage or absolute number of free and reduced price meal eligible children in each census block group. The tool also can help communities identify traditionally underserved areas. Once need is assessed, potential outreach partners and summer feeding site locations can be identified. Users can add information such as public and private schools, universities, school districts, Rural Development and U.S. Department of Housing and Urban Development housing, libraries, and churches.

- The online route builder tool (http://www.fns.usda.gov/mobile-route-maker) for summer meal sponsors, vendors and state agencies is overlaid on the Capacity Builder and connects the dots for children in rural areas where transportation challenges continue to hinder children’s access to healthy meals during the summer. Sponsors can identify potential summer meal sites for mobile feeding by identifying gaps in service in the neediest areas, plan the most efficient monitoring routes, and find routes to local food vendors to create fresh local meals (http://www.fns.usda.gov/farmtoschool/farm-summer). In addition, self-prep central kitchens and vendors can find the best route to deliver meals to each summer meal site.

- The Summer Meals Site Finder (http://www.fns.usda.gov/summerfoodrocks) was developed to help children, parents, and others quickly and easily find summer meal sites near them. The site finder, available for use at no charge, is a web-based application that also works on tablets, smartphones, and other mobile devices. Stakeholders and partners can access real-time data online.