# Informed & Ready:

Questions Part C and Part B 619 Program Leaders Should Ask About an Early Childhood Integrated Data System

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Many young children with disabilities participate in multiple programs before they start kindergarten. In addition to receiving both early intervention (EI) or early childhood special education (ECSE) services, they might attend Early Head Start, Head Start, public prekindergarten, or child care programs. Many states are building an Early Childhood Integrated Data System (ECIDS) so they can answer questions about the number, characteristics, and outcomes of the children who are served in multiple programs. An ECIDS collects and reports data from early childhood programs across agencies within a state for a specified number of years.

An ECIDS can be an extremely valuable resource for Part C and Part B 619 programs, but realizing its full benefit requires that state staff be informed about what sharing data means for their program. This brief is designed for Part C and Part B 619 state staff (referred to as Part C and Part B 619 program leaders) in states that either do not have an ECIDS or whose ECIDS does not include data from Part C or Part B 619. The brief discusses the benefits for Part C and Part B 619 program leaders of participating in an ECIDS, explores some of the questions that these leaders need to ask as part of deciding whether to contribute data to their state's ECIDS, and recommends additional resources. It is designed to help programs reap maximum benefits from ECIDS participation while ensuring that their interests are protected.
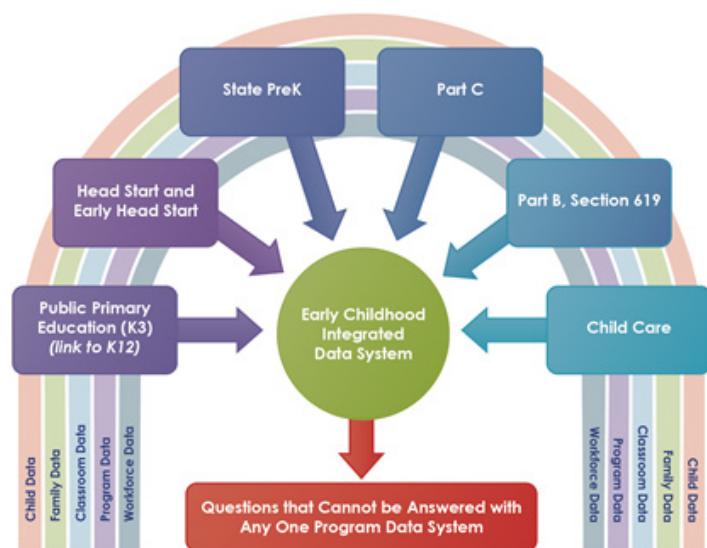
Many programs contribute data to an ECIDS
Source: https://nces.ed.gov/programs/slds/pdf/whatisanecids.pdf

What is an ECIDS?

An ECIDS contains a set or subset of data linked together for the purpose of answering questions and for analyses for those participating in data-driven decision making. It is not real-time information; rather, each program contributes data that are integrated into the ECIDS to be linked with data from other early childhood programs. See the brief *An Early Childhood Integrated Data System* for more information.

The Value of ECIDS Participation for Part C and Part B 619

The importance of including young children with disabilities in community–based settings creates a pressing need to know how many are enrolled in such settings and what kinds of outcomes they experience.

The immediate benefits of Part C and Part B 619 programs are evident to families and program staff. However, many stakeholders, including families and legislators, have questions about how these children perform after leaving the programs. Stakeholders also want to know about the short- and long-term outcomes for children who participate in multiple early childhood programs. The importance of including young children with disabilities in community-based settings creates a pressing need to know how many are enrolled in such settings and what kinds of outcomes they experience. Being part of the state's ECIDS allows Part C and Part B 619 programs to answer such critical questions. For example, an ECIDS could provide the programs with the percentage of EI or ECSE children who attend general early care and education programs and the proportion of these children who are in programs deemed to be of high quality.

As part of the process of moving toward ECIDS participation, Part C and Part B 619 leaders need to inform themselves about what participation means for their program. The remainder of this document contains a series of questions that program leaders should discuss with their state ECIDS team. Some background is provided for each question, along with potential challenges and several possible options for a state. Each state is different in its approach to an ECIDS for a variety of reasons, such as priorities, capabilities, and interests. An ECIDS can be designed in more than one way and governed in more than one way.

Critical Questions That Require an ECIDS

DaSy compiled a set of critical questions that a state data system for EI or ECSE should be able to answer. Answering several of the questions requires the linked data an ECIDS provides. Examples are the following:

- What percentage of children enrolled in EI/ECSE are served in general early care and education programs (e.g., Early Head Start, Head Start, home visiting, child care, state pre-K)?

- What are the characteristics of children with IFSP/IEPs who are spending time in general early care and education settings (e.g., disability category, race/ethnicity, limited English proficiency, age, socioeconomic status)?

- What percentage of children or families in EI/ECSE are receiving other public services (e.g., The Special Supplemental Nutrition Program for Women, Infants, and Children; foster care; children with special health care needs; child protective services; supplemental security income)?

See the Critical Questions on the DaSy website for more examples.

A. How will the data be protected?

An ECIDS is separate from the Part C or Part B 619 data system, but The Family Educational Rights and Privacy Act (FERPA) and Health Insurance Portability and Accountability Act of 1996 (HIPAA) rules and regulations, particularly those related to personally identifiable information, must still be followed. State regulations may be more restrictive than FERPA or HIPAA and also must be followed. The ECIDS staff should be able to provide all the policies for handling, protecting, and disclosing data within the ECIDS and assurances that they are compliant with all state and federal privacy laws.

Usually, an ECIDS contains only deidentified data; the data are stored by a child identifier that affords protection of the personally identifiable data in the ECIDS. A set of common elements are selected—for instance, first name, last name, and date of birth—and a formula is used to match these elements with an individual child and then assign a single identifier. Ensuring that data are properly deidentified and that all FERPA and HIPAA privacy regulations are applied prior to sharing the data internally and/ or externally significantly reduces risk.

If outside sources are able to request the data, the ECIDS staff should have procedures in place for processing applications. If the state is not providing summary-level and/ or properly deidentified data, these procedures should include establishing a memorandum of understanding or other data sharing agreement. Being familiar with these policies and the documentation will help establish realistic expectations between program staff and the ECIDS staff. Part C and Part B program leaders should establish parameters with the ECIDS staff about when their program staff should be consulted before executing any agreement to disclose any Part C or Part B 619 program data.

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Resources for Question A: Protection of Data

- DaSy maintains a collection of privacy and confidentiality resources. See Privacy and Confidentiality for more information.
- The Privacy Technical Assistance Center's brief Integrated Data Systems and Student Privacy provides information about protecting education data privacy with integrated data systems.

B. What is the ECIDS data governance structure? How will Part C and Part B 619 be represented in that structure? How do decisions made by the data governance body affect the data a program collects?
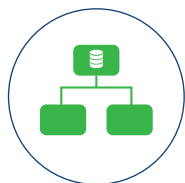
Data governance—the overall management of the availability, usability, integrity, quality, and security of data—is an important topic for any data system but even more so when multiple data sources are being integrated. Program leaders should expect the ECIDS team to have an existing or planned process and structure for data governance. Data governance may be informal or formal. In a formal structure, generally a data governance body is composed of representatives of the various contributing programs or agencies, and established processes and approvals take place for any decisions regarding the ECIDS. Informal data governance is done without established boards, processes, or approvals. With informal data governance, decisions may be made by only a few people and may not consider the complexities of integrating data from multiple sources. A quality ECIDS will have formal data governance. Part C and Part B 619 programs should be cautious when joining an ECIDS with informal data governance given potential concerns about the safety and security of the data being contributed to the ECIDS. For more information on data governance, including the pitfalls of informal data governance, see Resources below.

If data governance is already in place, Part C and Part B 619 program leaders should educate themselves about all established and planned processes and approvals. For instance, if the program later wants to contribute an additional data element, what is the process for adding it to the ECIDS? Is the approval of specific staff members needed before it can be added? How long do approvals take? Program leaders should also confirm that any unique data governance needs of their programs are addressed within the current structure or that accommodations are made if they are not currently addressed.

Program leaders should know the membership of the data governance body if one exists. Generally, there are two options for data governance body representation: (1) Part C or Part B 619 staff are part of the data governance body, or (2) the program will be represented by another state official such as the special education director representing all special education interests, including Part B 619. If Part C or Part B 619 staff are members of the data governance body, it is important that they attend data governance meetings and actively participate in data governance decisions. If another individual represents the Part C or Part B 619 program, program leaders should expect to work closely with that person to make sure the program's interests are represented.

> **Data governance is an important topic for any data system but even more so when multiple data sources are being integrated.**

Resources for Question B: Data Governance

- A subcomponent of the DaSy framework is dedicated to data governance and management. The framework provides information about how the data governance should be established.
- Data Governance and Management Toolkit – A resource containing information, guidance, and templates to assist Part C and Part B 619 program staff with creating or enhancing their data governance policies and procedures.
- Avoid the Pitfalls of Informal Data Governance – A brief that explains what can happen with information data governance and why it is important to formalize it.

C. What data will Part C or Part B 619 be expected to share?

As the program representatives, Part C and Part B 619 leaders should work with the ECIDS team to determine the appropriate data for the program to contribute. Some states include all of a program's data in the ECIDS whereas others include only a subset related specifically to the purpose of the ECIDS. A good rule of thumb is to start by considering the program's goals for participating in the ECIDS as well as the state's goals for the ECIDS overall to determine what type of data to include. A program's goals for sharing data in the ECIDS potentially stem from the need to answer critical questions that require integrating data across programs. If other special education programs have already contributed data to the ECIDS, Part C and Part B 619 program leaders could consult the ECIDS data dictionary to see what types of elements and element metadata[1] have been included. Each of the participating programs and agencies should have entries in the data dictionary. The dictionary should include the metadata that will be considered in the integration process.

In addition to what data to contribute, program leaders should discuss how often to provide the data to the ECIDS team. Typically, this is negotiable based on when the program receives data from the ECIDS. At a minimum, programs should expect to submit the data to the ECIDS team at least once a year. If a program has data collection windows, it can typically expect to provide data at the end of a window, when the data are less likely to be in flux, unless there is a need for the initial data and final data (e.g., a reporting requirement with a date earlier than the close of the data collection window). Sometimes, more frequent contributions are warranted (e.g., a report required for state accountability requires the real-time data available from the program). These scenarios, the program's data collection periods, and the ECIDS team's schedule for loading data should be discussed to determine the best schedule for contributing data.

If the ECIDS staff are requiring that a program contribute all its data and the Part C or Part B 619 program wants to provide only a subset of the data, program leaders should ask why all the data are needed. The ECIDS staff should be able to clearly articulate why the additional data are needed. Best practice is to provide data with an identifiable existing or future need.

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[1]Element metadata refers to information about the element such as definition, length, option set codes and definitions, purpose of data collection, validation rules, transformation rules, and element source.

D. What will be required of Part C or Part B 619 staff?

Contributing data to an ECIDS requires some effort on the part of program staff. Initial efforts will be more extensive than ongoing efforts. Contributing programs can expect to dedicate resources initially to decide how data will be extracted and any transformation rules that will be needed and to validate the correctness of the data at each step of the process, from taking a copy from the source system to loading it into the ECIDS. One of the more time-consuming tasks in determining transformation rules is agreeing on the metadata. This task includes aligning elements from the Part C or Part B 619 data system with those in the ECIDS, including an element's name, definition, and option set. Depending on the size of the program's data system and the expertise of the staff, state leaders can expect development of the program query to take anywhere from days to several weeks. The Part C or Part B 619

data staff will be able to provide a more accurate estimate. Once the program query is developed, only ongoing maintenance will be needed. This will involve updating the query for any new file names, time periods, and/or data elements to be included in the export.

After the data are loaded into the ECIDS, best practice is to run some basic queries to ensure the data loaded correctly and that the system generates the correct counts based on a comparison with the original data system. For example, a simple query of children's gender will show the number of male and female children for the program in the ECIDS. This number should be compared with the count in the program's own data system. When the figures match, program leaders can be confident the data loaded correctly. Making several of these comparisons will be useful to ensure that all the data are correctly entered into the ECIDS.

Resources for Questions C, D, E: Data Integration

- The Center for the Integration of IDEA Data's Data Integration Toolkit offers steps, tasks, and timelines to help understand and navigate the data integration process.
- The U.S. Department of Health and Human Services and U.S. Department of Education recently released *The Integration of Early Childhood Data*, which helps states understand various ways to integrate early childhood data.

E. What data will Part C or Part B 619 be able to access? How? How frequently?

Programs contributing data to an ECIDS should expect to access their own information in the ECIDS with few administrative barriers. Program offices can access their own data in myriad ways, depending on the ECIDS' capabilities. Data generally are provided in a download that can be imported into the program staff's data analysis tool of choice or as a report within a specified tool. Access may be limited to specified program staff. Programs should expect program staff to be able to access read-only versions of their data. Updates to the data in the ECIDS should be handled by the information technology staff.

How frequently a program will be able to access the data will depend on how the ECIDS output is configured. Sometimes, an ECIDS also has a reporting tool that can be used by program staff with appropriate access. In this case, the ECIDS data are available at any time. In other cases, a request must be submitted to an ECIDS staff member, in which case the program staff will have delayed access to the data subject to the ECIDS staff member's workload. This will decrease the frequency with which they can access data. Program leaders should clarify both the process and the frequency for accessing the data early in the discussion.

How frequently a program will be able to access the data will depend on how the ECIDS output is configured.

Summary

An ECIDS can be a powerful tool for Part C and Part B 619 program leaders for addressing important questions about children's participation in multiple programs either simultaneously or sequentially. When data on children who receive EI or ECSE services are included in an ECIDS, the leaders of these programs can understand the full picture of what young children with disabilities in the state are experiencing. Armed with that information, they can begin to examine and address how multiple programs are contributing to child and family outcomes. Participating in a state's ECIDS requires that Part C and Part B 619 leaders be informed stakeholders. The questions and considerations discussed here provide a brief introduction to some of the issues program leaders need to understand as they move to ECIDS participation. Part C and Part B 619 leaders are encouraged to consult some of the additional resources listed here to deepen their understanding of these issues. Moving to ECIDS participation is an exciting journey, but program leaders need to be informed travelers.

Participating in a state's ECIDS requires that Part C and Part B 619 leaders be informed stakeholders.

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