



Key Part C Data

Considerations During COVID-19

July 13, 2020

Introduction

Since the start of the COVID-19 pandemic, state Part C systems have been altering policies, procedures, and practices to address public health challenges and the service needs of children and families. Assessing the impact will most likely require additions to existing data collection. Similarly, this newly collected information can help states make decisions about how best to move forward in the coming months. State Part C programs should consider planning for and collecting additional data in response to COVID-19-related program changes and then use these data to respond to system and practice questions and planning throughout the crisis.

The purpose of this document is to provide a preliminary set of data considerations for Part C systems to understand the evolving impact of COVID-19 on services, programs and administrative activities, support decision-making, and assist in planning for future needs.

These considerations have been informed in part by the experiences of Part C lead agencies. In partnership with state Part C staff, DaSy intends to add to this preliminary set of considerations over time as states' experiences with the COVID-19 emergency continue. DaSy is also creating tools to assist states in collecting, reporting, and using the data necessary to make effective decisions related to COVID-19. DaSy appreciates the willingness of state Part C staff to continue to share their challenges and solutions as we all continue to deal with this health emergency.

This document is not intended to be an in-depth coverage of all data collection activities routinely conducted by Part C programs. DaSy recognizes that Part C systems require documentation of many activities and steps to address specific administrative requirements, some of which occur at the state level and some at the program level. This document will not address some of these, e.g., those that relate to general supervision, correction of noncompliance, determining need for compensatory services, fiscal decisions, personnel needs and procedural safeguards. Many of these are impacted by COVID-19 and some may be covered in future DaSy documents and webinars.

Addressing Ongoing Challenges

Many state agencies do not have all the data needed to manage the crisis and most likely have to collect new or additional data. The challenges states are facing to ensure the availability of necessary data during COVID-19 are widespread and evolving. Most of these challenges originate from the numerous and ongoing changes all states are facing during COVID-19. Documenting these changes will provide context for your data and help inform analyses and decision-making.

Change seems to be the norm.

- Changes are occurring at the system level and at the local level, including the local EI program level.
- These changes may involve pauses in some activities and/or changes in the way those activities are conducted.

- These ongoing changes present challenges in terms of what information to collect and how often.

Changes are complex.

- Changes occur across multiple levels and changes at one level may impact other levels.
- Changes are impacted by multiple variables, e.g., states may allow the resumption of in-person services, but local programs may not because of local city or county mandates, which may vary across the state.
- Changes are not necessarily gradual or progressing in one direction. For example, a specific state or county can move towards reopening and then return to previously lifted restrictions if COVID-19 numbers increase.

Family experiences will also continue to change over the course of the pandemic.

- Family circumstances are changing over time, e.g., siblings participating in remote learning, family members working at home, access to technology. These may affect their decisions at any point in time on their ability and willingness to engage in virtual services.
- Changes made by the state and/or local providers regarding service delivery may also impact changes in family decisions, e.g., declining evaluations or services.

Part C Data Considerations

The considerations related to COVID-19 and Part C data are organized into three sections:

The first section, *System-Level*, addresses the state- and system-level changes states and local programs have made in response to the pandemic, e.g., changes to practices, policies, and procedures. Much of the data about these changes provide contextual information, that is, they describe the context in which the program activities occur. This kind of information will be important for the analysis, interpretation, and use of state and program-level data as it relates to decision-making and the impact of COVID-19. For example, state systems may report monthly data on the number of children found eligible for Part C. Without contextual data on when the system paused evaluations, accurate interpretations of the data on individual children and families are not possible.

The second section, *Family- and Child-level*, outlines additional data that could be collected related to individual children and families including services provided and decisions made by parents. States already collect and use many of these data elements. In response to COVID-19, additional detail and response options may be needed to help fully describe and document the status of program activities.

The third section, *Considerations for Data Collections, Analysis, and Reporting*, offers suggestions on analysis and reporting to assist states in communicating about services and program activities during COVID-19 by clarifying the context of the data, using data visualization, and creating reports that depict changes over time.

Section 1: State/System-level Considerations

The following are suggested items that states should consider documenting because they can provide contextual information for the analysis and use of the data for Part C systems during COVID-19. For all/most of the following, consider whether the item applies to your state system and if so, whether there is variation by type of service, location, discretion of local program, and access to technology. This information should guide decisions about your documentation efforts.

- Closure of Statewide System/Local EI Program (if applicable) (no staff activity or service delivery)
 - Start and end dates for closure of state agency
 - Start and end dates for closure of each local EI program (or subset of programs)

- Referrals, Evaluations, Eligibility Determination
 - Start and end dates for pause and/or change in taking referrals
 - Start and end dates for pause and/or change in conducting evaluations, e.g., policies/procedures for virtual evaluation
 - Start and end dates for pause and/or change in policies and/or procedures for conducting eligibility determinations, e.g., tools, eligibility criteria, use of informed clinical opinion, need for re-evaluations and at what points in time
- Services
 - Start and end dates for pause and/or change in the development of initial (or interim IFSPs)
 - Start and end dates for pause and/or change in providing IFSP services
 - The date when in person services were first canceled (if different than the closure dates above)
 - Date when virtual services were first made available to families
 - Date when in-person visits resumed
 - Detail for the phasing in of in-person services as they resume (e.g. does it vary by location in the state, including circumstances whether it is specific families, locations, services)
 - Start date (and frequency) of procedures for the assessment and documentation of family interest in virtual services
 - Start and end dates for how and when IFSP reviews take place
 - Data elements necessary to determine the need for and provision of compensatory or make-up services
- Outcomes
 - Start and end dates for pause and/or change in collecting child outcomes data, e.g., changes in policies and/or procedures for assessment, assessment tools, team meetings, determining entry and/or exit ratings
 - Start and end dates for pause and/or change in collecting family survey data, e.g., changes in policies and/or procedures for administration of survey
- Transition
 - Start and end date for pause and/or change in method or timeline of notification at the state level
 - Start and end date for pause and/or change in method or timeline of notification at the local level
 - Start and end date for pause and/or change in method or timeline in inviting the LEA to the transition conference
 - Start and end date for pause and/or change in method or timeline for conducting the transition conference
 - Start and end date for any COVID-19-related change in policies and procedures for continuing to serve children under Part C beyond their third birthday
- Data Collection
 - Start and end dates to changes in data system
 - Addition of dropdown options for COVID-19-related reason(s) for noncompliance, new service codes/methods, ability to capture data in text field or case notes
 - Documentation of data external to the state data system, e.g., contacts to parents about interest in virtual services, contacts to parents about technology access and assistance. Some of these data may be collected at multiple points in time, and these data may or may not be collected/aggregated at the state level

- Changes to 618 data collection, making sure additions/changes map to existing reporting categories. Address continuing to serve children after age 3
- Start and end dates for collection of fiscal data, e.g., reimbursement of services, costs of technology (devices, internet access), personal protective equipment (PPE)
- Other
 - Start and end dates for other COVID-19-related changes to policies and procedures, (e.g., frequency and nature of parental contacts)
 - Start and end dates for changes to methods for obtaining parental consent
 - Start and end dates to fiscal policies related to reimbursement (by service type)
 - Start and end dates for assessment/documentation of provider need for and access to technology
 - Start and end dates for assessment/documentation of family need for, access to, and availability of technology
 - Start and end dates for assessment/documentation of family interest in virtual services
 - Data elements needed to track personnel shortages and need for re-assignment
 - Start and end dates for staff working in state physical office
 - Start and end dates for local program staff working in physical office

Section 2: Family- and Child-level Considerations

States are likely already collecting and using many of the following are data elements. In response to COVID-19, additional detail and response options may be needed to help fully describe and document the status of program activities.

- Evaluations and Eligibility Determination
 - Reason for eligibility, change in reason e.g., from informed clinical opinion to developmental delay, pending evaluation) and date
 - Method of evaluation, e.g., virtual; date of evaluation
 - Reason family declined eligibility evaluation, e.g., not interested/not the right time, etc.—initial vs. later, change vs. not; no access to technology—initial vs. later (with tech assist)
 - Reason family declined services, e.g., not interested/not the right time; no access to technology
- IFSP/Service delivery
 - Document IFSP development/review/revision due to COVID-19
 - Changes to service (type, frequency, method) and dates
 - Family decline service(s), reason(s), length of time for “on-hold,” and date(s)
- Transition
 - Transition steps and services: delay, reason, date
 - Transition conference delay, reason, date
 - Determination of ongoing need for services after age 3 (Part B evaluations/eligibility/initiation of services)
- Exiting
 - If adding COVID-19-related exit reason(s), map to 618 Table 3 federal exit reasons

Section 3: Considerations for Data Collection, Analysis, and Reporting

Data collection

As discussed above, for states to be able to describe COVID-19-related changes and understand their impact, they will need to collect specific kinds of information. Furthermore, these data will need to be collected and examined at multiple timepoints as the impact of COVID-19 on early intervention services and families' decisions continues to evolve. Most state agencies will not have all the data needed to manage the crisis which means that they will need to collect new or additional data.

Considerations for data collection:

- Make changes to the state data system to capture additional COVID-19-related child-level data for future statewide analysis, e.g., adding new codes such as “telehealth.”
- If necessary, collect information in a text field in the data system, in case notes, or through Excel files collected from programs. Use a standardized list of codes to save time during analysis.
- Regardless of what has been done thus far, there is still time to plan and implement data collection strategies and changes. There is still opportunity to consider the recommendations in this document and make changes to inform ongoing decision-making.

Analysis and reporting

Multiple types of reports can be used for effective decision-making and to examine the impact of COVID-19 on various aspects of your Part C program and the children and families you serve. Consider helping users understand the context and implications of the reports by using data visualization and accompanying the data with one or two key take away messages. As discussed above, it is important to provide the context in which these disruptions or changes occurred, and to be transparent in terms of the uses and limitations of the data.

Considerations for analysis and reporting include:

- Create year over year change reports. These are simple descriptive graphs (reporting n by time) and are easy to read and understand. For example, show a bar chart of referrals by months for 2019 and 2020. Highlight any marked changes in 2020 referrals and show dates of important COVID-19-related state or local actions.
- Create similar year over year change reports for other steps of the Part C process, (e.g., eligibility determinations, exits, transitions to 619).
- Create reports to demonstrate changes in service delivery; of particular interest might be comparing in-person vs. teleservices over time. If data are available, show the breakdown of families who received teleservices by demographic characteristics such as race/ethnicity, socioeconomic status, and/or geographic location (e.g., local programs). For families who did not receive teleservices, consider an analysis by reason, (e.g., lack of technology, lack of internet access, lack of interest, or other family circumstances.)
- COVID-19's impact may vary within your state and therefore disaggregating the statewide data by region or local program may be necessary to show such variation. Alternatively, consider separate regional/local reports with comparisons to the state for each. Accompany the quantitative data with an accurate description of the status of the region/local program over time in terms of COVID-19-related restrictions to help the report viewer understand some of the variance across regions.

- Because of the dynamic nature of changes at the state- and region/local-level, and among families, consider running the same reports at different points in time. For example, interest in, access to, and acceptance of teleservices may change over time.

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About Us

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