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Using Unique Identifiers to Promote Data Sharing Between Part C and Part B

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INTRODUCTION

Obligations of state education agencies (SEAs) and Part C lead agencies set forth by the Individuals with Disabilities Education Act (IDEA) pertaining to early childhood transition from Part C to Part B of IDEA are described in several regulatory and guidance documents including Part C draft regulations (34 CFR Part 303), Part B regulations (34 CFR Parts 300 and 301), and an Office of Special Education Programs (OSEP) policy guidance letter dated February 11, 2004.¹ Requirements include providing data to document progress on Indicators related to early childhood transition as a part of a state's Annual Performance Report (APR) to OSEP. Indicator 8 on the Part C APR requires data to be reported on the percent of children exiting Part C who received timely transition planning that includes an Individualized Family Service Plan (IFSP) addressing transition steps, a transition conference and notification to the local education agency (LEA) if the child is potentially eligible for services under Part B. Part B APR Indicator 12 requires states to report the percentage of children who are referred by Part C prior to age three, found eligible for Part B and have an Individualized Education Program (IEP) in place by their third birthdays.

These two APR indicators, C8 and B12, require states to have systems and procedures in place that allow them to collect accurate student-level data between two different programs that are often administered by different state agencies. Using unique identifiers that are assigned to children identified in Part C and remain assigned to the child as they transition to Part B is one aspect of data sharing that some states have instituted in order to improve early childhood transition outcomes for their students and the state's ability to report on indicators C8 and B12 specifically.

This document reports on the experiences of six states that currently use unique identifiers within their data systems to track students from Part C to Part B and provides information on the circumstances surrounding the development of such systems, what the systems look like, benefits and challenges. This document was prepared by Project Forum at the National Association of State Directors of Special Education (NASDSE) as part of its cooperative agreement with the U.S. Department of Education's Office of Special Education Programs.

¹ Letter to Elder, <http://www.ed.gov/policy/speced/guid/idea/letters/2004-1/elder021104ifsp1q2004.pdf>

METHODOLOGY

Project Forum conducted a mini-survey via email in January 2009 of state education agencies (SEAs) and Part C lead agencies in all states, territories and other non-state jurisdictions (referred to as 'states') to ascertain which states currently use unique identifiers to track students between Part C and Part B. Thirty-two states responded to the survey (51% response rate) and of those, seven indicated that they currently use some type of unique identifier between Parts C and B. Six of these seven states indicated availability and interest in participating in interviews with Project Forum for the purpose of this document. The participating states include *Connecticut, Georgia, Kansas, Minnesota, Missouri* and *Utah*.

Project Forum staff developed an interview protocol in collaboration with OSEP and the Mid-South Regional Resource Center (MSRRC); early input from representatives of the National Early Childhood Technical Assistance Center (NECTAC)² and the Data Accountability Center at Westat (DAC-Westat)³ also supported the development of the protocol. Project Forum staff interviewed representatives designated by state special education directors and/or Part C coordinators via telephone during February 2009. Attempts were made to include staff members from both Part B and Part C programs in the interviews. Project Forum staff sought input from both programs prior to finalizing the document for all interviewed states.

COMMON THEMES

Motivation and Benefits

A majority of the states interviewed cited their need to provide accurate and complete data to OSEP for the purpose of Indicators C8 and B12 on their APRs as a primary reason for developing a system to use unique identifiers. States with separate Part C and B data systems often transferred information in preparation for transition manually and for some, it was completed on paper. State employees found that there were instances of "missing" children, meaning their information somehow became lost, mostly due to coding issues and miscommunication. Therefore, states determined that the accuracy of data reported could be improved by streamlining the data sharing process. States were also interested in improving their ability to make accurate data-driven decisions about programs and services and more broadly, improve the transition experience for children and families at the local level.

In addition to improving the accuracy of data reporting, states noted several other benefits to using unique identifiers that bridge Part C to B. These include: improved efficiency in transfer of information; potential to improve early childhood transition outcomes at the local level; the ability to answer longitudinal questions to inform program and policy improvements; and increased or improved interagency collaboration.

² NECTAC is an OSEP-funded technical assistance center to support the implementation of Part C and §619 of IDEA (early childhood special education) in the states.

³ DAC is an OSEP-funded center to support the collection, analyses, and use of state-reported IDEA data. DAC is charged with evaluating state data capacity and providing technical assistance to improve data quality.

Funding

Two states (*Georgia* and *Kansas*) used a U.S. Department of Education General Supervision Enhancement Grant (GSEG) for data sharing improvements to initiate and/or support the development of their unique identifier systems. Other states had unique funding circumstances depending on whether Part C lead agency was at the Department of Education along with the Part B program, which program initiated the project and whether or not they developed the system as a part of a special project or as part of their ongoing duties.

Lead Agency Differences

Not surprisingly, responding states where the SEA also serves as the Part C lead agency (*Missouri* and *Minnesota*) experienced fewer complications and challenges in developing, implementing and operating their system of using unique identifiers. Specifically, interagency agreements or memoranda of understanding (MOU) were not necessary, funding did not need to be shared between two agencies and the need to address confidentiality laws governing the transfer of personally identifiable information was minimized.

States in which the Part C lead agency is not the SEA (*Connecticut, Georgia, Kansas* and *Utah*) engaged in greater levels of sustained interagency collaboration, thorough exploration and explication of their legal requirements regarding confidentiality of personally identifiable information and discussions of how any purchases or improvements would be funded. These states had to determine how the unique student identifiers would actually be assigned to students receiving services in Part C. They also had to develop a technical mechanism for the cross-agency data systems to “talk” to each other in a way that met the obligations of any interagency agreements or MOUs spelling out confidentiality requirements.

Existing Data Systems

It is important to note that all interviewed states had adequate existing data systems for both Part B and Part C in place prior to developing a system that would allow data sharing via unique identifiers. In some cases, one system needed to be updated to a greater extent than the other, but each had a data system with which to work.

Remaining Challenges

While each state communicated that the benefits of having the system of unique identifiers for children in Part C and B far outweighed not having it, a few challenges remain. Assigning multiple numbers to the same child can be a problem with name changes (or cases where the parent registers the child under slightly different names), moves and transfers in and out of foster care. Additional data elements need to be consulted (such as mother’s maiden name) in order to verify identity. State interviewees cautioned that it is important to continually review any MOUs or interagency agreements to ensure compliance with current Family Educational Rights and Privacy Act (FERPA) and Health Insurance Portability and Accountability Act (HIPAA) regulations as these may change on timelines different from that of IDEA reauthorization.

STATE EXPERIENCES—DIFFERENT LEAD AGENCIES

Connecticut

Stakeholders

The Part B, 619 and Part C coordinators in the state of *Connecticut* have worked together closely on issues of transition for over a decade, despite being housed in separate agencies. Several other stakeholders were involved in the development and implementation process including Part C and B data managers, the Part B state director, Part B information technology division, and Part B and C legal counsels. All of these parties agreed on the goal of implementing a system of unique identifiers to bridge Part C and B; therefore, the development process consisted primarily of determining how to achieve this goal both practically and legally.

Snapshot of the System

The SEA maintains a web-based student registration system that assigns unique identifiers to individual children in preschool to grade 12 for both special and general education. Since 2006, Part C has been able to access the student registration system to assign unique identifiers to children served in their system. Part C and B continue to maintain separate databases for the purposes of collection, analysis and reporting of data for their populations. The difference is that now Part C can use the student registration system to assign unique identifiers and data can be shared, or linked, between the systems by using this identifier.

Development and Funding

The development work included adding a field in the Part C data system to house the new unique identifier, adding a code in the Part B system for Part C children, addressing the legal requirements of FERPA and updating the MOU between the agencies to include the protocol for data sharing in accordance with FERPA. The lead agency for Part C, the Department of Developmental Services, is designated under state law as an LEA; in essence, the Part C lead agency operates a “unified school district” for the provision of early intervention to eligible children age birth to three. This status allows the agency to access and utilize the student registration system to assign the unique identifiers to its population within the legal requirements of FERPA and in accordance with the protocols set forth in the MOU. No special funding was assigned to support the development and implementation of the unique identifiers; all activities were funded through existing staff positions as a part of their regular work responsibilities.

Georgia

Previous System Issues

In 2008, *Georgia* implemented a data sharing system that enabled the assignment and use of unique identifiers for children served by Part C (the identifier was already used for students in preschool through grade 12). Prior to this system, Part C provided transition information to Part B via paper and pencil documentation, which resulted in errors and missing students. Additionally, the data that Part C provided to Part B was often not specific due to differences in district zones (health districts do not cover the same geographic area

as school districts), terminology and codes used to protect the confidentiality of personally identifiable information. For example, a geographic region that encompasses several school districts would be notified that there would be three students with autism reaching age three in the month of April; this lack of specificity limited the ability of the LEAs to prepare to receive the incoming preschoolers or to know if those particular students were even identified to be enrolled in Part B.

Stakeholders

The stakeholders involved in the development and implementation of the data sharing system included state representatives from Part B SEAs and C lead agencies including information technology personnel. The team also sought input from Part C and B service providers and parents at different points during the process.

Development and Funding

The SEA and Part C lead agency, the Department of Human Resources, continue to maintain separate databases for their populations. The new data sharing system allows specific data elements from the Part C database to be transmitted to the Part B database via the unique identifier. Legal counsels for both agencies spent significant time and care in addressing the confidentiality requirements of both FERPA and HIPAA. The end result was the development of an explicit cooperative agreement between the agencies that specifically deals with data sharing between agencies. This had to be in place before the project could move forward.

Development and implementation of this project was funded by a GSEG grant beginning in January of 2006. The grant was applied for, administered, and facilitated by a third party, Westat. The grant provided \$685,000 that was used to pay for Westat's administration of the grant and facilitation of the development process, information technology contractors to design and implement the data sharing software application, training of personnel, upgrades to the Part C database, improved security for the Part B database and development of a manual and informational DVD. The information

technology departments of both lead agencies estimate that the annual maintenance (including data cleansing and verification) and technical assistance associated with the data sharing application costs approximately \$20,000.

Challenges

Challenges in the development process included staff turnover that stalled the process and difficulty sustaining the interagency collaboration necessary to work out the terminology and confidentiality issues prior to addressing the technology needs. *Georgia* staff indicated that the involvement of Westat was particularly helpful. Westat was able to provide instrumental facilitation of the necessary interagency collaboration.

TIPS from Georgia:

1. Clarify terminology at the beginning; data elements may be called different things by the different programs.
2. Base the data linkage project on your existing systems.
3. Carefully address all confidentiality requirements and document in a MOU or interagency agreement.

Kansas

Stakeholders

Kansas held two initial meetings for stakeholders during the 2005-2006 school year. Part C and B data managers, state program staff and legal counsel from both agencies, representatives from NECTAC and Mountain Plains Regional Resource Center (MPRRC), Part C (Kansas Department of Health and Environment) and B (Kansas Department of Education)

“Strong, positive working relationships are important. There’s give and take on both sides; one can’t get “choosy” about whose money, time, or space is being used...The completed project benefits everyone in the systems.”
--Kansas Part C Staff Member

service providers, state Interagency Coordinating Council staff, state Special Education Advisory Council representatives, and parent representatives participated in one or both of these meetings. The participants discussed the data elements they would need to share between the C and B data systems in order to meet their goals, an existing MOU between the two lead agencies developed during a prior data sharing effort in 2002, confidentiality issues pertaining to FERPA and HIPAA that needed to be addressed and the process they would use to assign the identifiers.

Snapshot of the System

The Part C program in *Kansas* functions as an LEA in the sense that it is able to send batch files to Part B data managers to receive assignment of unique identifiers. Part C and B continue to maintain separate databases for their students; the agreed upon data elements are shared between the two systems by using the unique identifiers.

Development and Funding

Initial groundwork on the data sharing concept started in 2002 with a GSEG grant for \$276,731; the grant funded initial meetings among stakeholders, the development of an interagency MOU and other related activities. NECTAC and the MPRRC facilitated the development of a state early childhood transition improvement plan. The programming necessary to implement the data sharing mechanism was completed by agency staff as a part of their assigned duties. Daily operation responsibilities are assumed by data managers in both agencies. Prior to data sharing between the Part C and Part B agencies, the Kansas Department of Education had developed a system for assigning unique identifiers to school-age students in response to data collection requirements for the No Child Left Behind Act of 2001 (NCLB). Expansion of the system to include using unique identifiers for Part B 619 and Part C data sharing required several years of planning and collaboration to implement.

Utah

Stakeholders

Both agencies’ leadership and data managers agreed to begin working together on this project in 2007. The Part B 619 director serves on the Interagency Coordinating Council and knew that Part C had spent two years investing in the development of a new database system. She saw an opportunity to link to this system in order to improve Part B data. State program staff, data managers and legal teams were involved in the development and

implementation of the project. The system, slated to be live by March 2009, will consist of separate Part C and B databases linked together via software that delineates specific data elements to be shared through the use of unique identifiers. The Part C program was given status as an LEA for the purpose of assigning these identifiers, similar to *Connecticut* and *Kansas*.

Development and Funding

Part B 619 bore the development costs for the software since Part C had just developed its own new database system and Part B 619 wanted to link to it. The state spent approximately \$80,000 for an outside contractor to develop the applications and expects to spend about \$60,000 more in 2009. Part B 619 staff felt that using the same contractor that designed Part C's new database system resulted in receiving the product quickly and inexpensively and reduced the time it took to learn how to use it. Staff members estimate annual maintenance costs for a two-year contract, including a new server, at \$1,500. After the second year of implementation, daily operating costs will be part of the agency's management budget.

"You have to know exactly what problem you're trying to solve [in order] to get the buy in. It helps that the APR was a focus...all [of us] agreed data-driven decisions are best."

--Utah Part B 619 Staff Member

Even though the Part C and Part B 619 staff had a history of collaboration, a great deal of time was spent discussing the idea and gathering buy-in from stakeholders prior to the agreement to begin developing the system. Legal counsel for both agencies were involved from the beginning to work out the confidentiality requirements of FERPA and HIPAA and design an appropriate protocol for shared data elements. Both agencies acknowledged that if the new system had created extra work for state staff or local providers, it would have been a barrier. In reality, they have found that it will significantly reduce work, particularly in terms of paperwork burden for Part C staff.

STATE EXPERIENCES—SAME LEAD AGENCIES

Minnesota

History

Minnesota has the longest standing system of using unique identifiers that bridge Part C and B; it has been in place since the late 1980s, prior to APR requirements. Unlike most other interviewed states, the original motivation for the unique identifier system was to improve the state's funding distribution to LEAs. Parts C and B in *Minnesota* are both administered by the SEA and it is a birth-mandate state (a state that chooses to provide a free appropriate public education to all eligible children from birth). Part C and 619 staff are all focused on early learning birth to five, which means the lines drawn by IDEA between the birth-3 and 3-5 populations are somewhat blurred. Confidentiality issues were also not a large concern for *Minnesota* since the data are part of students' educational records housed within the same agency.

Minnesota staff has enjoyed the many benefits of this system for several years. The system promotes efficiency and improved outcomes because the Part C exit data become the Part B entry data, students are easily tracked between the programs, the state is able to provide

accurate data for the purpose of their APR indicators and the ability to do all this enabled the state to clarify and implement an improved early childhood transition policy.

Snapshot of the System

There is one state database of student information for all children ages birth to 21. Data managers who work with this database do so in the course of their regular job duties. Demographics (including the unique identifier), enrollment, program eligibility, amount of services and least restrictive environment are the data elements included in this system. The unique identifier allows state staff to link data to a second database that houses outcomes data for the purpose of fulfilling reporting requirements of IDEA and NCLB and a third database that includes family outcomes data.

Missouri

History

Missouri initiated development and implementation of a system of unique identifiers for all public school children, including children with disabilities served under Part B, and extended the system to the Part C program, which in *Missouri* is implemented by the SEA. Various stakeholder groups, including school districts and state staff, were involved in the development process. The primary driver for the whole system was the need to make data-driven decisions at the state level.

Development and Funding

FERPA and HIPAA issues were not relevant since both programs are administered by the SEA. *Missouri* purchased an “off the shelf” product in cooperation with several other states for an initial cost of \$524,000 funded by a combination of state and federal funds. The annual maintenance cost for the system is \$71,000. It is important to note that this is the cost for the entire data system, not simply the part that allows data sharing to occur between Part C and Part B. Approximately .5 full time equivalency (FTE) of state staff is dedicated to supporting the users of the system and less than .25 FTE of staff is used to manage the hardware and software housed within the SEA.

RECOMMENDATIONS

All states interviewed highly recommended that other states develop similar systems to allow data sharing between Part C and B programs using unique identifiers. The benefits are numerous, simple and significant. The end result is clearly worth the intensive early work required to carefully identify and address all related FERPA and HIPAA guidelines and the technical aspects of designing a mechanism that enables two data systems to “talk” to each other.

States with different lead agencies for Part C and B noted that existing collaborative relationships between the agencies was a key to their success. *Georgia* found it beneficial to hire a third party to facilitate and manage the process. In addition to having collaborative relationships in place, having up to date, functional, free-standing databases for each program also made the process of linking them much smoother. A project to completely redesign one or both program’s data systems would have added to the burden and costs.

Finally, one state encouraged federal cross-agency partnerships to assist in interagency collaboration by providing additional technical assistance and guidance on this issue. These offices may include OSEP, the U.S. Department of Education Family Policy Compliance Office (administers FERPA) and U.S. Department of Health and Human Services Office for Civil Rights (which administers HIPAA). Federal guidelines for addressing the FERPA and HIPAA issues with respect to data sharing between Parts C and B would support states that have not yet embarked on this process. Guidance might include a template from which individual states' legal counsels could craft an interagency agreement.

RESOURCES

Miller, F., Hornback, M., Weir, R., Robinson, N., Beever, S., Lucas, A., & Leinen, J. (YEAR). Sharing data for C8 and B12: Conversations with states. Retrieved February 19, 2009 from <http://www.ideadata.org/docs/Sharing%20Data%20for%20C8%20and%20B12-Miller-Hornback-Weir-Robinson-Beever-Lucas-Leinen.pdf>

National Early Childhood Transition Initiative. (2008, March). Designing and implementing effective early childhood transition processes. Retrieved February 19, 2009 from <http://www.nectac.org/~pdfs/topics/transition/ECTransitionPaper.pdf>

NECTAC. (2008, May). Overview of IDEA/APR early childhood transition requirements. Retrieved February 21, 2009 from www.nectac.org/~ppts/topics/transition/desgining_implementing_transition.ppt

The National Early Childhood Transition Initiative
<http://www.nectac.org/topics/transition/ectransitionta.asp>

Example of interagency agreement allowing datasharing between Part C and B for the purpose of early childhood transition for the state of Illinois.
http://www.rfcnetwork.org/images/stories/FRC/spp_mat/2007_Nov/intergovernmentalagreementdatatransferringisbedhs.pdf

The National Early Childhood Technical Assistance Center, State Guidance and Policy Relating to Transition from Part C
<http://www.nectac.org/topics/transition/stateex.asp>

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