



Commonwealth of Massachusetts
The Office of Health and Human Services
Department of Public Health
75 State Street, Boston, MA 02108-4619

CHARLES D. BAKER
Governor

KARYN E. POLITO
Lieutenant Governor

MARYLOU SUDDERS
Secretary

MONICA BHAREL, MD, MPH
Commissioner

Tel: 617-624-6000
www.mass.gov/dph

March 10, 2016

Steven T. James
House Clerk
State House Room 145
Boston, MA 02133

William F. Welch
Senate Clerk
State House Room 335
Boston, MA 02133

Dear Mr. Clerk,

Pursuant to line item 4513-1020 of Section 2 of Chapter 46 of the Acts of 2015, please find enclosed a report from the Department of Public Health entitled *Early Intervention SASID (State Assigned Student ID) Project*.

Sincerely,

Monica Bharel, MD, MPH
Commissioner
Department of Public Health

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Charles D. Baker
Governor

Karyn Polito
Lieutenant Governor



Marylou Sudders
Secretary

Monica Bharel, MD, MPH
Commissioner

SASID Assignment for Early Intervention Children

**Department of Public Health
Executive Office of Education
Department of Elementary and Secondary Education**

March 2016



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Legislative Mandate

Pursuant to line item 4513-1020 of Section 2 of Chapter 46 of the Acts of 2015:

*For the early intervention program; provided, that the department shall report quarterly to the house and senate committees on ways and means the total number of units of service purchased and the total expenditures for the units of service paid by the department, the executive office of health and human services and third party payers for early intervention services for the following service categories: home visit, center-based individual, child-focused group, parent-focused group and screening and assessment; provided further, that the department shall make all reasonable efforts to secure third party and Medicaid reimbursements for the services funded in this item; provided further, that funds from this item shall be expended to provide respite services to families of children enrolled in early intervention programs who have complex care requirements, multiple disabilities and extensive medical and health needs; provided further, that priority shall be given to low- and moderate-income families; provided further, that the department shall submit to the house and senate committees on ways and means a report on the number of families served by the program and the amount of funds appropriated in this item granted to qualified families not later than January 8, 2016; provided further, that no claim for reimbursement made on behalf of an uninsured person shall be paid from this item until the program receives notice of a denial of eligibility for the MassHealth program from the executive office of health and human services; provided further, that MassHealth shall cover the costs incurred for the transportation of MassHealth members who participate in the early intervention program; provided further, that nothing in this item shall give rise to or shall be construed as giving rise to enforceable legal rights to any such services or an enforceable entitlement to the early intervention services funded in this item; provided further, that the department shall provide written notification to the house and senate committees on ways and means 90 days before any change to its current eligibility criteria; provided further, that no eligibility changes shall be made prior to January 1, 2016; provided further, that these funds may be used to pay for current and prior year claims; provided further, that the department shall provide services to eligible children through 1 service delivery model and shall not determine eligibility for services based on family insurance status; **provided further, that not later than March 1, 2016, the department shall submit to the executive office for administration and finance and the house and senate committees on ways and means a status update on the early intervention state assigned student identifier pilot program; and provided further, that the update shall include a cost estimate for expanding the pilot to additional sites in fiscal year 2017***

DPH SASID Report Summary

The purpose of the Early Intervention/SASID Pilot project is to issue a state assigned student identifier (SASID) to children participating in early intervention programs with the long-term goal of tracking and evaluating educational and developmental outcomes for these children, improving delivery of services and determining cost savings. Participation of a family is contingent upon gaining informed written consent.

This project, established with funds from the Fiscal Year 2014 budget, remains a priority for the Department of Public Health's (DPH) Early Intervention program (EI) in their efforts to obtain outcome data regarding the impact and effectiveness of early intervention services.

The Pilot

The Early Intervention/SASID (EI/SASID) Pilot project began its implementation in April 2014 with seven EI programs participating. The seven sites are:

1. First Steps Infant-Toddler Services for South Berkshire
2. Riverside Early Intervention Program/Needham
3. Criterion – Wachusett Early Intervention Program
4. South Bay Early Intervention Program – Fall River
5. South Bay Early Intervention Program – Lowell
6. South Bay Early Intervention Program – Brockton
7. South Bay Early Intervention Program – Worcester

The purpose of the pilot is to learn from providers how to improve communications to parents regarding the benefits of the project, the best times to approach families to participate, and best practices for the management of this information. The pilot is beneficial in that it provides real data for the benefit of improving validations for increased data accuracy prior to DPH receipt and provides feedback for the improvement of processes. During this time enhancements to the original design of DPH system and transmission interfacing processes have improved and reports have been developed.

The seven EI pilot programs represent each of the state geographical regions and are of varying size and demographic make-up. Participation of a family in this pilot program is contingent upon parental authorization to release data to DESE that identifies the parent's child as an EI participant. A consent form for parental authorization for data sharing was approved by both DPH and the Department of Elementary and Secondary Education (DESE). The pilot programs have and will continue to provide feedback on this form to ensure that it communicates the purpose of the parental authorization clearly to both clinicians and families.

(Attachment A – Consent Form)

Obtaining Consent

Parents are presented with the “Parent Authorization for Early Intervention Data Sharing” form (consent for data sharing) at the initial six month Individualized Family Support Plan (IFSP) Review meeting. The establishment of relationships between the family and EI staff and a better understanding of EI services enable the family to make a more informed decision regarding the value for giving consent for data sharing at the six month timeframe. Families who do not provide consent at this time will again be presented with the consent form at some point in time prior to exiting. All families with eligible EI children who have received six or more months of EI services will be presented with the consent form. This process will capture all children, regardless of eligibility type, and will provide a broad pool of participants.

Completed consent forms are scanned and then emailed via the state's Secure Mail system to the DPH where data entry occurs. In the future, the Individualized Family Support Plan (IFSP) will be revised to include a check off that consent was obtained by the family. A copy of the consent form is kept at the EI program in the child's file for documentation and DPH auditing purposes.

Families always have the option to "opt-out" of consent after having given consent. Families will be provided with contact information for communicating their desire to opt-out. If an opt-out occurs while the child is still active in EI and the family informs the program then this will be documented in the child's EI record and the child's data record will not be included in any future evaluation efforts.

EI/SASID State System

Executive Office of Education (EOE) Systems

The processing of matching children and assigning SASIDs for children outside of EOE has been on hold since December 2014 while EOE/DESE is working on a design to improve their legacy system into one that can more readily respond to SASID assignment for agencies outside of EOE. The EOE data system was not originally built to receive and transmit SASID information between agencies but has expanded over time to accommodate for this vital function. EOE is now in the process of designing a new system that will meet all current and future requirements necessary for handling standardized SASID assignment for all its interfacing agencies.

DPH Systems

During the first few months of implementation many of the processes at DPH were manually intensive. EI programs scan and email consents to DPH and then the DPH Office of Data Entry enters the data and creates files that get uploaded to the EI SQL server residing at MITC. Many of the original SQL processes at the beginning of this project were manual. But over time, DPH has improved its system to automate many of these processes. Data entry, however, is still a highly intensive manual process.

DPH was able to successfully automate the linkage of Massachusetts Birth Records to EI SASID data for the purpose of ensuring data accuracy of EI children born in Massachusetts. DPH is in the process of attempting to develop a system that will identify and report near matches between DPH and birth data. Near matches will be manually reviewed and then flagged as either a match or not. This should help in increasing the number of children having consent to be transmitted to EOE for SASID assignment and future evaluation.

After an intensive phase of testing DPH was successful with the submission of two files prior to October 2015 and received back data stating if a SASID was assigned to a child or not. This information is now included as part of EOE's Edwin Analytics data system and will be used in the future for evaluative purposes. EI pilot programs continue to submit consent forms and that information is processed at DPH. Approximately 1,200 forms have been processed by DPH and are awaiting transmission to EOE.

EI/SASID Data and Reports

During the first six months of the pilot, between April and September 2014, there were over 900 consent forms submitted to DPH for processing. This high volume of forms included all children at the programs who had received six or more months of EI services. Since that time DPH receives an average of 50 forms per month that come from children at their six month IFSP review.

The following reports were developed over the past year for SASID reporting:

- *SASID Follow-Up Report* - identifies birth dates and/or gender that do not match to the Birth Records for follow-up for corrections by EI providers
- *SASID Summary Report* – provides the number of SASID assigned children
- *SASID Summary Program Report* – provides the number of SASID assigned children by EI program
- *SASID File Counts* – provides counts of records transmitted to EOE

A report is in the process of being developed to report children having a consent form, regardless of whether they were assigned a SASID or not. It is the expectation that the vast majority of EI children will be assigned a SASID and this report will provide information to DPH and the pilot programs during the “on-hold” phase for EOE.

(Attachment B – EI SASID Summary Report)

DPH Communication

The Department communicates about the EI/SASID Assignment Pilot project with the Early Intervention community at bi-monthly Interagency Coordinating Council (ICC) meetings. Status updates are also shared through the EI monthly newsletter and monthly EI webinars. Pilot programs continue to provide ongoing feedback regarding the usability and family friendliness of the consent form as well as all processes to be managed at the provider sites. Status updates about the progress of the initiative are provided to the pilot programs through emails and discussions with their EI regional specialist.

Future Activities

Beyond the Pilot

Additional funding will allow DPH to expand the number of EI programs participating in the EI/SASID project by providing incentives to allocate training to clinicians and program administrators. The Early Intervention Training Center (EITC) staff will assist in the initial and ongoing training needs of future participating programs. A training toolkit can be developed with the assistance of the pilot programs to include materials to assist staff in engaging families to participate and in obtaining informed consent. An online training module/voice over PowerPoint

can be developed for ongoing training of service coordinators. A training curriculum on the expectations for local program administration can also be developed.

Capturing Electronic Consents

EI will be evolving from its current legacy system to a web-based system within the next two to three years. SASID activities have been included in the RFR requirements document so that the current manual processing of paper consent forms can be transitioned to electronic forms and signatures stored in the new system.

SASID Sharing with DPH

The current data agreement between DPH and EOE does not allow the SASID to be shared with DPH. DPH is the only agency where EOE does not include the SASID on the retuning response or outcome file. This means that EOE must have a separate and distinct process for file creation for DPH. This also means that as certain conditions change for EI children, such as a name change due to an adoption, a future match in the EOE system for the purposes of evaluation may not occur. DPH will begin to meet with the DPH Privacy and Legal offices, and appropriate EOE personnel to discuss a new data sharing agreement that would allow EOE to share the SASID with DPH for EI children.

Evaluation

DPH hired the Evaluation Office of Massachusetts General Hospital to develop a proposal for an evaluation plan. The proposal included the following activities and products:

- Interviews with key stakeholders
- A review of the literature
- Consultation with public health and special education professionals from New York
- Creation of a SASID Evaluation Advisory Committee
- Evaluation of delivery and continuity of EI and DESE Services (to enhance systems integration)
- Assessment of Expenditures and Cost Savings
- Proposed products
 - Development of a short-term implementation evaluation plan and analysis
 - Development of a long-term outcomes evaluation plan
 - Tracking and Assessment of Child Outcomes

Development & Funding Resources Needed

Funding to support the inclusion of additional EI programs; the development of additional training products; enhancement of file transfers between DPH and EOE; addressing the legal requirements of sharing the SASID between EOE and DPH; and evaluation activities is required to support the continued development and implementation of the EI/SASID Assignment Pilot project.

(Attachment C – Budget)

Attachment A

SASID Consent Form



The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Department of Public Health
250 Washington Street, Boston, MA 02108-4619

DEVAL L. PATRICK
GOVERNOR
JOHN W. POLANOWICZ
SECRETARY
CHERYL BARTLETT, RN
COMMISSIONER

Tel: 617-624-5200
Fax: 617-624-5208
www.mass.gov/dph

CONSENT FORM

Parental Authorization for Early Education Data Sharing

Dear parent/guardian,

We are constantly working to improve services to families across the Commonwealth and would like to request your help in evaluating services your child currently receives through the Early Intervention (EI) program provided by the Massachusetts Department of Public Health (DPH).

In an effort to create stronger programs for all children, we are seeking permission to share data about your child, such as your child's name, date of birth, city or town of birth and residence, with the Massachusetts Department of Elementary and Secondary Education (DESE). DESE oversees special education in the Commonwealth's schools and collects and maintains data for students who are found eligible for services from age three to 22. DPH would like to share information about your child with DESE for the purpose of helping the state know whether participation in EI results in:

- Reducing the number of children who need special education services when they enter public school
- Reducing the level of services needed for special education prior to reaching the third grade, a milestone year for many children
- Helping young children with delays and disabilities do better in school, from preschool through high school

Information about your child's participation in EI will not be available to teachers or officials in the public schools unless you provide it directly. The information being shared includes what you provide on the parental consent form as well as other information that will help show the benefits of EI services. It will be used anonymously for summary reports only. To make this possible DPH needs your permission to share information about your child with DESE. You can provide approval for data sharing by completing the parental consent form.

Confidentiality of your child's identifying information is protected under state and federal law and by the authorizations in this consent form.

To Withdraw Consent: Contact Patti Fougere, Department of Public Health
250 Washington Street, 5th Floor, Boston, MA 02108 (617) 624-5975; patti.fougere@state.ma.us

English - v1.0 - Mar 2014

PARENTAL AUTHORIZATION FOR EARLY EDUCATION DATA SHARING

Child's FIRST Name (as it appears on the birth certificate or adoption papers)

[illegible]

Child's MIDDLE Name (as it appears on the birth certificate or adoption papers) ☐ No middle name

[illegible]

Child's LAST Name (as it appears on the birth certificate or adoption papers)

[illegible]

Gender

☐ Male ☐ Female

Child was adopted/In process of adopting ☐ Yes ☐ No

Born in Massachusetts ☐ Yes ☐ No ☐ Unknown (If Unknown skip City/Town of Birth)

Child's City/Town of Birth ☐ Unknown

[illegible]

Child's Current City/Town of Residence

[illegible]

I have had a chance to ask questions and get answers about this form. I understand that I may contact the EI program at DPH, by phone or in writing at the address or phone number located at the bottom of the parental consent letter, to withdraw my consent for release of my child's information in the future. Unless I withdraw my consent, this consent will remain valid through my child's attendance in high school. If I do withdraw my consent, I understand that information about my child that has already been shared cannot be returned.

PARENT/GUARDIAN (PLEASE PRINT)

PARENT/GUARDIAN SIGNATURE

Date _____

Office Use Only
DPH Client ID:
____/____/____
SecureMail .PDF Consent Form to MDPH at eiiis@eophhs-sfed.state.ma.us

Attachment B

DPH SASID Report



Early Intervention Information System

SASID Fiscal Year Report

Fiscal Year 2015

Summary counts of all SASID consent forms received from Early Intervention

SASID CONSENT FORM STATUS

TOTAL (<i>children having a consent form</i>)	924
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Sent to DESE

SASID was assigned	814
SASID was not assigned (<i>DESE unresolved conflict</i>)	0
	814

Not sent to DESE: Data Issues

Near Matches (<i>will get resolved in the future</i>)	40
Born in MA, birth data not found	27
No EIIS Match	41
EIIS Match, No IFSP	2
	110

Percent of children having valid data sent to DESE	88%
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Percent of children sent to DESE and assigned a SASID	100%
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Attachment C

Fiscal Year 2017 Proposed Budget to Fully Support SASID Efforts

(based upon previous budget submission)

STAFFING and CONTRACTORS	
DPH / EHS IT Staffing and Contractors	
Data Entry, Data Management	
DPH / EHS IT Engineering and Support	
Project Manager, Applications Developers and Architects	
Associated software and equipment costs	
TOTAL DPH / EHS CONTRACTED SERVICES and SUPPORT (E56)	150,000
EOE Contractors	
SASID Resolution	16,000
TOTAL CONTRACTED STAFF and SERVICES	166,000
IT SYSTEM ENHANCEMENTS	
SASID Assignment System Enhancements (EOE/ESE)	159,000
TRAINING AND RELATED COSTS FOR DPH EI SITES (MM)	
1 scanning/fax machine for each pilot program	1,500
Stipends for providers (release time \$150.00/day 3-5 participants per program)	3,750
Provider Incentive for pilot programs (\$5,000 each program x 5)	25,000
TOTAL TRAINING and SITE COSTS	30,250
EVALUATION design/Assessment of analysis needs	35,000
TOTAL ESTIMATED EXPENSES	390,250

As presented, the funding to support on-going SASID assignment activities is based upon prior state budget awards. It is important to note that funding was cut by “9C” reductions and for the past two fiscal years but has progressed without dedicated funding.