



University at Buffalo
The State University of New York
School of Public Health and Health Professions

POPULATION HEALTH OBSERVATORY



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EARLY CHILDHOOD OUTCOMES DATA SYSTEM ANNUAL REPORT 2006

In collaboration with:
New York State Department of Health, Division of Family Health, Bureau
of Early Intervention
and
University at Binghamton, Institute for Child Development

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EXECUTIVE SUMMARY

The federal government has increased its focus on measuring and improving the results being achieved through state early intervention programs, preschool special education and special education systems for children and youth with disabilities. Under a recent federal mandate, each state was required to develop a State Performance Plan ([SPP](#)) to measure how successful these programs are in improving outcomes for children, and their families, who are served by such programs. In the State of New York, the SPP involved gathering information beyond that routinely collected by the Early Intervention Program ([EIP](#)) of the State Department of Health (NYS DOH), Division of Family Health, Bureau of Early Intervention. The EIP Director and staff worked in collaboration with the Population Health Observatory of the University at Buffalo, School of Public Health and Health Professions ([UB-PHO](#)); and the Institute for Child Development of the University at Binghamton ([UBN-ICD](#)) to develop a data system to collect, manage, analyze and report child and family outcomes proposed in the SPP. The collaboration was funded by a Memorandum of Understanding (MOU) between the NYS-DOH and the UB-PHO, with a sub-contract to the UBN-ICD.

In 2005 and early in 2006, the [EIP](#) Director and staff developed data collection instruments and sampling plans, in consultation with the [UB-PHO](#) and the [UBN-ICD](#), to survey families of current participants in the EIP and to assess the developmental status of new entries into the program. The sampling plans were designed to produce representative statewide samples of families of children concurrently served by the EIP program and of children entering the program for the first time in the fall of 2006. In the first half of the first year (2006) of the planned five year collaboration, development of the human and IT infrastructures necessary to measure and evaluate child and family outcomes of program participants were planned. EIP stakeholders (*i.e.*, parents, facilitators/managers, evaluators, service providers, and municipalities) were informed and educated about the federal mandate and impending implementation of the [SPP](#). Education and training materials were developed and prepared for dissemination on-line via a website and off-line in the form of a training manual. The UB-PHO and the UBN-ICD received, copied and mailed the child and family surveys and instructions to county EIP program offices and families of the EIP participants sampled from the KIDS data system, respectively. The UBN-ICD trained stakeholders how to properly complete the respective surveys and began providing technical assistance and ongoing support to stakeholders. The UB-PHO planned and began developing capacity (human and IT) for data entry, cleaning, and quality control; data management and security; and data analyses and reporting necessary to fulfill the US Department of Education, Office of Special Education Programs ([OSEP](#)) reporting requirements.

Data collection of both child and family outcomes began in September, 2006. Data on several newly developed indicators of child and family outcomes were collected, stored, and analyzed. [UB-PHO](#) faculty collaborated with the [EIP](#) Director and staff to evaluate program performance as defined in the [EIP State Performance Plan](#). Results were reported to the [OSEP](#) early in 2007. The first mandated transfer of data to the OSEP was made in February, 2007.

The following activities by the [UBN-ICD](#) and the UB-PHO reflect their respective contributions to the successful completion of this task:

UBN-ICD Activities

The [UBN-ICD](#) developed a website designed to inform and educate stakeholders about the State's need to evaluate the effectiveness of the [EIP](#) by measuring both child and family outcomes of participating children and their families. The website ([UBN-ICD-EIP](#)) provides online training and

technical assistance to stakeholders to help them correctly respond to items on the child or family outcomes surveys and presents answers to frequently asked questions about each survey. The educational and training materials on this website and additional information were made into an off-line training manual, which was duplicated and disseminated to stakeholders who did not have internet access or who preferred to study the materials off-line. In addition to these on/off-line education and training materials, the UBN-ICD developed and runs telephone and email help-desks to further assist parents, facilitators/managers, evaluators, or service providers in completing the respective surveys.

UB-PHO Activities

The [UB-PHO](#) provided statistical consultation to the [EIP](#) Director and staff during the planning and implementation of the [SPP](#) sampling plan, collaborated with them to perform program evaluation, and provided data capacity for evidence based program management. UB-PHO activities in the first year focused on the development of human and IT systems to build data capacity. Activities included: (1) Conventional pencil and paper data collection and data entry of child and family outcomes data; (2) Database creation and data management; (3) Summarization, analysis, interpretation, and reporting of data for program evaluation and program administration; and (4) Administrative functions required for project support and coordination.

In 2004, the DOH was a recipient of a General Supervision and Enhancement Grant ([GSEG](#)) to develop child and family outcomes for New York State. The GSEG involves a three phase project to: (1) identify child and family outcomes using Concept Mapping methodology; (2) implement a field test to determine the extent to which child and family outcomes identified through the Concept Mapping methodology can be successfully implemented; and, (3) evaluate the overall success of the GSEG initiative in identifying measurable child and family outcomes for the [New York State EIP](#). Both the [UBN-ICD](#) and the [UB-PHO](#) have been involved in (GSEG) activities and will continue to support that project.

Phases 1 and 2 of the project have been completed. As of August 17, 2007, there were 230 responses to the [GSEG](#) field study survey. Records for each have been entered and a data base has been created. Plans for analysis will be finalized at the meeting of the GSEG core advisory group in Albany on September 10-11, 2007. Data analysis and reporting responsibilities will be shared by the Department of Education at the University of Miami ([UM-DOE](#)), Florida, and the [UB-PHO](#). The UM-DOE will measurement analyses (*e.g.*, Item analysis and validity and reliability checks), while the UB-PHO will relate child outcomes (no delay, moderate delay, severe delay, on each of five domains) to demographics and severity of disability. The GSEG field study data are currently being linked to KIDS data system records to add demographic and severity variables to the GSEG database.

Data Summary

A sample of 2265 families of former or currently exiting participants of the [NYS EIP](#) was obtained by randomly sampling [EIP](#) participating children's records from the State's KIDS data system. Sampling was restricted to children who had participated in EIP for at least six months. Their families were then surveyed to obtain responses to 22 items on the Family Outcomes Survey ([FOS](#)). A total of 580 families responded (25.6%). The planned sample consisted of a geographically proportional sampling of counties and additional samples from New York City (NYC). Preliminary analyses indicated that the entire sample of 580 families was not biased by the over sampling from NYC. Thus, we present results in this report for the entire sample.

Federal requirements call for an evaluation of performance on Items 17, 19, and 20 of the [FOS](#): (17) EIP services have helped me and/or my family communicate more effectively with the people who work with my child and family; (19) EIP services have helped me and/or my family know about my child’s and family’s rights concerning EIP services; and (20) EIP services have helped me and/or my family do things with and for my child that are good for my child’s development. The 22 items of the survey were ordered from easiest to most difficult on which to achieve satisfaction. It is assumed that satisfaction on a given dimension guarantees satisfaction on all more easily satisfied dimensions. An overall satisfaction score for each responding family was obtained from a [Rasch Model analysis](#). Each family’s score was compared to threshold values for each item to determine whether the family was satisfied (*i.e.*, expressed strong or very strong agreement with the item’s statement.) with regard to the corresponding dimension. The threshold values were determined by the National Center of Special Education Accountability Monitoring ([NCSEAM](#)) from a sample of 1750 families from eight states. The key items of interest, ordered from easiest to most difficult, and their corresponding thresholds were: Item 20, 516; Item 19, 539; and Item 17, 556. If a family’s score was greater than 539, for example, then the family was “satisfied” that participation in the program had helped them know their rights about EIP services. Table 1 shows the percentage of responding families whose level of satisfaction with the program exceed each of the thresholds for each of these key items.

Table 1

Percentage of Families Satisfied with Three Items 17, 19, or 20 on the Family Outcomes Survey (n=580)		
Item Number and Description	Percentage above Threshold	95% Confidence Interval
Item 17 (Threshold Score = 556) EIP services have helped me and/or my family communicate more effectively with the people who work with my child and family	65.7	(61.8, 69.6)
Item 19 (Threshold Score = 539) EIP services have helped me and/or my family know about my child’s and family’s rights concerning EIP services	71.7	(68.1, 75.4)
Item 20 (Threshold Score = 516) EIP services have helped me and/or my family do things with and for my child that are good for my child’s development.	82.4	(79.3, 85.5)

Overall, the average score for the 580 families sampled was 620. This score falls between the thresholds for the fourth and fifth most difficult items on the [FOS](#). This means that the average New York State family was “satisfied” with all but four of the 22 items (Items 1, 2, 5, and 8). Improvement in the program, therefore, can be achieved by helping families to: Participate in typical activities for children and families in their community (Item 1); improve their quality of life (Item 2); know where to go for support to meet their needs (Item 5); and keep up friendships for their child and family (Item 8).

The statewide sampling plan of the [SPP](#) originally called for a geographically proportional sampling of 800 children, newly evaluated by the [EIP](#) from September through November of 2006,

with outcomes to be reported using the Child Outcomes Entry Summary Form ([COESF](#)). This number was reduced by one, due to special circumstances in Hamilton County. Thus a roughly proportional sample of n=799 children from geographic strata were targeted by the [SPP](#)'s statewide sampling plan. Of these, 383 were to be sampled from New York City (NYC) and 416 from the rest of the state. As of July 1st, 2006, 179 child data forms had been received from NYC (47%) and all 416 had been received from the other municipalities (100%), for an overall sample of 595 and response rate of 74.5%. Additional samples of 635 EIP participants in Nassau County and 635 in Suffolk County were planned for more in depth local evaluation of the EIP program. Child survey forms were completed for 253 and 154 of these over-sampled children (40% and 24%), respectively. Thus, the [UB-PHO](#) received COESF's for a total of 1002 (416+179+253+154) of the 2069 (416+383+635+635) children (48%) who were targeted for the statewide or local samples. Of the 1002 children for whom COESFs were returned, 884 were known to be eligible for EIP services. The forms for two of these were missing information on all of the child outcomes of interest. Hence, these two were deleted, leaving 882 children who were known to be EIP eligible. Of these, 485 were in the geographically proportional statewide sample, while 154 and 243 additional children were included in the locally representative samples for Suffolk and Nassau Counties, respectively.

In this report, the geographically proportional statewide sample was combined with the extra samples from Nassau and Suffolk Counties to obtain one dataset of children who were known to be eligible for [EIP](#) services. Tables presented herein provide summaries of the entire sample of 882 eligible children. Tables summarizing the results for only the 485 eligible children in the geographically proportional statewide sample were similar to those for the entire sample of 882. Thus, the larger dataset will be used to obtain baseline summaries of child outcomes that will be compared in future years to the same summaries statistics obtained when these 882 children leave the EIP. Table 2 presents baseline results for Items 7A, 7B, and 7C of the [COESF](#).

Table 2

Key Child Outcomes for EIP Eligible Children in the Entire Statewide Sample for 2006				
Baseline Data from 2005-06 Child Outcomes Entry Summary Form (COSF)				
Total N = 882	Children Functioning at Level <i>Comparable to Same-Age Peers</i> (Rating of 6-7 on COSF item) at Entry to the EIP		Children Functioning at Level <i>Below Same-Age Peers</i> (Rating of 1-5 on the COSF item) at Entry to the EIP	
	Percent	N	Percent	N
Positive social-emotional skills (including social relationships)	42%	371	58%	511
Acquisition and use of knowledge and skills (including early language /communication)	25%	218	75%	664
Use of appropriate behaviors to meet their needs.	20%	176	80%	705

The children in the sample of 799 new enrollees to the [EIP](#) in 2006 will be tracked until they exit the program, at which time an exit survey form will be submitted and added to the [ECO](#) Data System's database. The comparison of exit to entry data will be made in subsequent years of the project to evaluate whether the program services improve outcomes.

INTRODUCTION

The New York State Early Intervention Program ([EIP](#)) is the statewide system of early intervention services for infants and toddlers with disabilities and their families under Part C of the Federal Individuals with Disabilities Education Act ([IDEA](#)), which mandates that states provide evaluation and intervention services to children 0 to 3 years of age who are developmentally delayed, disabled, or at high risk for developmental delay. In 2001 the cost of the program, nationwide, was just under \$2.9 billion. Federal funding of Part C was \$592 million, while states contributed \$2.3 billion. The federal Office of Special Education Programs ([OSEP](#)) monitors State progress in implementation of IDEA. Until recently, however, there was no attempt to evaluate the benefits of the program to children or families. Recently, OSEP mandated that each state submit a State Performance Plan ([SPP](#)) with data on key child and family outcomes to be used in subsequent evaluation of the impact of the Part C services provided. OSEP also funded the development of early childhood outcomes survey instruments by the Early Childhood Outcomes (ECO) Center and a Family Outcomes Survey ([FOS](#)) form by the National Center for Special Education Accountability Monitoring ([NCSEAM](#)).

The State of New York proposed, in its SPP, to use the items of an adaptation of the [ECO](#) Center's Indicator 3 as the child outcomes in a statewide evaluation of the EIP program. Items from an adaptation of the FOS that was developed by the NCSEAM were chosen as the family outcomes for the proposed evaluation. Neither the child outcomes nor the family outcomes are collected by the State's KIDS data system. Thus, a new data collection and data management system was proposed to collect information on these outcomes. The State Department of Health ([NYS DOH](#)), Division of Family Health, Bureau of Early Intervention contracted with the Population Health Observatory of the University at Buffalo, School of Public Health and Health Professions ([UB-PHO](#)); and the Institute for Child Development of the University at Binghamton ([UBN-ICD](#)) to develop a data system to collect, manage, analyze and report these new child and family outcomes. The first year (2006) of a planned five-year collaboration was funded by a Memorandum of Understanding (MOU) with the UB-PHO, with a sub-contract to the UBN-ICD. The contract became fully executable in June, 2006, with funding retroactive to January, 2006. In this report, we present the work done by the UB-PHO and the UBN-ICD in fulfillment of the contract.

The goals of the first year of the collaboration were to: (1) build data collection and data entry capacity to construct a database of outcomes for the families of a cohort of children who had been served by the program for at least six months and who had exited, or were soon to exit, the program and to enter the data collected; (2) build data collection and data entry capacity to construct a database of baseline outcomes of a cohort of children who were newly entering participants of the program in 2006; (3) build an IT data management, analysis, and reporting system; (4) analyze child and family outcomes and to interpret and report results; and (5) to develop and implement a data security and confidentiality protocol and standard operating procedures that ensure security and confidentiality of data. This report of activities to achieve these goals is organized roughly according to these goals. First we describe the [SPP](#) sampling plans of child and family outcomes.

SAMPLING PLANS

In 2005 and early in 2006, the [EIP](#) Director and staff developed data collection instruments and sampling plans, in consultation with the [UB-PHO](#) and the [UBN-ICD](#). A yearly survey of 2265 families of former [EIP](#) participants, or current participants who were soon to exit the program was planned to obtain family outcomes for each of the five years 2006-2010, using the [FOS](#). The outcomes for Indicator 3 of the [ECO](#) Center's child outcomes were planned for use to assess the developmental status of a cohort of 799 new entries into the program each year, plus a one-time

over-sample in a given year for each municipality, totaling 16,883 over the five year period. The sampling plans for family and child outcomes were designed to produce yearly representative statewide samples of families of children who had been served previously for at least six months by the EIP program and of children entering the program for the first time, respectively. The plan for newly entering children also was designed to produce a cumulative local sample for each municipality over the five years that was sufficient to accurately estimate local outcome rates.

Sampling Plan for Child Outcomes

Sampling Schedule

The DOH's EIP Director and staff planned enrollment of a Statewide, structured random sample annually of children entering the EIP anew each year. Both entry and exit data will be collected for these samples of children to measure and report Indicator 3 child outcomes in annual performance reports (APRs) submitted to [OSEP](#). In addition, to meet Federal [IDEA](#) requirements on the State to report to the public on the performance of *local early intervention programs*¹ at least once during the time period covered by the 2005-2006 State Performance Plan, the Department's sampling plan included a schedule for the selection and identification of locally-representative samples of children participating in each of the fifty-eight municipal EIPs. The sampling schedule is presented in the Table 3 below.

The sampling scheme was designed to produce sample sizes large enough to ensure high confidence (95%) that the proportion of EIP eligible children with age appropriate response to Indicator 3 items on the [COESF](#) would be estimated with an error 0.05 or less. Sample size requirements were calculated under the assumption of a 50%² response rate, the fact that 50,855 children less than 3 years old were referred to the program during the 2004-05 program year, and the assumption that the distribution of referrals among municipalities would be the same as that observed in 2004-05. These same assumptions were used to determine cumulative locally representative sample sizes for each of the fifty-eight municipalities that provide 95% confidence of estimating local response rates to within an error of 0.05.

Table 3
Sampling Schedule for Child Outcomes Data Collection

Geographic Coverage for State and Local Reporting	Time Frame for Sample Enrollment and Collection of Exit Data
Geographically proportional structured sample for NYS and locally representative samples for Nassau and Suffolk (Long Island)	Enrollment: Beginning September 2006 Exit: March, 2007 - August 2010
Geographically proportional structured sample for NYS and locally representative samples for Small Enrollment	Enrollment: Beginning July 2007

¹Local early intervention programs are defined by New York State as the municipal early intervention program administered by each of the fifty-seven counties and New York City.

² The estimated response rate is designed to account for attrition due to ineligibility determinations and other factors which may result in a child not continuing in the program; this is a conservative estimate. The sample size for each municipality's contribution to the State sample is proportional to the total number of children in the EIP who reside within the municipality. A minimum sample size of three children has been established for low population counties.

Counties (less than 100 EI referrals annually)	Exit: January 2008 – June 2011
Geographically proportional structured sample for NYS and locally representative samples for Medium Enrollment Counties (100 or more but less than 300 EI referrals annually)	Enrollment: Beginning July 2008 Exit: January 2008-June 2012
Geographically proportional structured sample for NYS and locally representative samples for Large Enrollment Counties (more than 300 EI referrals annually) (excluding Nassau, Suffolk, and NYC Counties)	Enrollment: Beginning July 2009 Exit: January 2010-June 2013
Geographically proportional structured sample for NYS and locally representative sample for NYC	Enrollment: Beginning July 2010 Exit: January 2011-June 2014

Details of the sampling plan by County are given below in Table 4. Note that the “Constant Yearly Target” is the base sample size to be collected in the municipality each of the five years, while the “One-time Over-sample” is the number of extra samples to be taken in the one year of over-sampling. Thus, the total sample size for each municipality over the five year period is calculated as 5 times that municipality’s “Constant Yearly Target” plus its “One-time Over-sample”.

Table 4
Planned Sample Sizes by Municipality

Municipality	Constant Yearly Target	One-time Over-sample	Year of Over-sample	Total Local Sample
Albany	7	432	2009	467
Allegany	3	45	2007	60
Broome	5	374	2009	399
Cattaraugus	3	156	2008	171
Cayuga	3	134	2008	149
Chautauqua	3	253	2008	268
Chemung	3	124	2008	139
Chenango	3	65	2007	80
Clinton	3	203	2008	218
Columbia	3	99	2008	114
Cortland	3	110	2008	125
Delaware	3	51	2008	66
Dutchess	9	374	2009	419
Erie	28	606	2009	746
Essex	3	56	2007	71
Franklin	3	74	2007	89
Fulton	3	70	2007	85
Genesee	3	113	2008	128
Greene	3	130	2008	145
Hamilton	2	2	2007	12
Herkimer	3	49	2007	74
Jefferson	3	209	2008	224
Lewis	3	43	2007	58

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Livingston	3	119	2008	134
Madison	3	91	2007	106
Monroe	21	581	2009	686
Montgomery	3	50	2007	65
Nassau	54	635	2006	905
New York City	383	366	2010	2251
Niagara	6	389	2009	419
Oneida	6	387	2009	417
Onondaga	14	538	2009	608
Ontario	3	186	2008	201
Orange	14	532	2009	602
Orleans	3	79	2007	94
Oswego	3	224	2008	239
Otsego	3	85	2007	100
Putnam	3	172	2008	187
Rensselaer	5	335	2009	360
Rockland	19	571	2009	666
Saratoga	6	392	2009	422
Schenectady	4	332	2009	352
Schoharie	3	41	2007	56
Schuyler	3	21	2007	36
Seneca	3	61	2007	76
St. Lawrence	3	110	2008	125
Steuben	3	146	2008	161
Suffolk	53	635	2006	900
Sullivan	3	183	2008	198
Tioga	3	81	2007	96
Tompkins	3	172	2008	187
Ulster	7	427	2009	462
Warren	3	141	2008	156
Washington	3	81	2007	96
Wayne	3	230	2008	245
Westchester	39	625	2009	820
Wyoming	3	59	2007	74
Yates	3	39	2007	54
TOTALS	799	12888		16883

Sampling Plan for Family Outcomes

Representative samples of families will be selected each year at the *State level* (for both State and locally representative samples) for collection of family outcome data, from among families of children who have received early intervention services for at least six months and *who have either exited, or will turn three and are expected to exit the [EIP](#) during the reporting year*. Systematic sampling procedures will be employed with proportional geographic representation to select a sample representative of the State as a whole each year. The State sample size was calculated to ensure 95% confidence that the estimated outcome rate would be within 0.05 margin of error, assuming an estimated response rate of 25%. These same parameters were applied to determine the sample sizes needed for each municipality to collect and report to the public each year on local EIPs (defined as municipalities in New York State), in accordance with the following schedule:

Table 5
Sampling Schedule for Family Outcomes Data Collection

Geographic Coverage for State and Local Reporting	Time Frame for Family Survey
Geographically proportional structured sample for NYS and locally-representative sample for NYC	July-August, 2006
Geographically proportional structured sample for NYS and locally-representative sample for Small Enrollment Counties (less than 100 EI referrals annually)	July-August, 2007
Geographically proportional structured sample for NYS and locally-representative samples for Medium Enrollment Counties (100 or more but less than 300 EI referrals annually)	July-August, 2008
Geographically proportional structured sample for NYS and locally representative samples for Large Enrollment Counties (more than 300 EI referrals annually)	July-August, 2009
Geographically proportional structured sample for NYS and locally representative sample for NYC	July-August, 2010

A base sample of 2210 families will be surveyed each year, with municipality sample sizes being in the same proportion as the proportion of [EIP](#) participants in the municipality. The sizes of the planned over-samples were not reported in the [SPP](#).

DATA COLLECTION AND DATA ENTRY

Processes for data collection and data entry of family and child outcomes were developed in 2006. Developing these processes amounted to building data collection and data entry capacity to be applied in each subsequent year to reliably and securely create databases of five years of family and child outcomes.

Family Outcomes

Family outcomes data were collected using the Family Outcomes Survey ([See Attachment A](#)). The process developed for handling and entering family outcomes data from the FOS forms is described below.

Data Collection

A pencil and paper data collection of Family Outcomes in 2006 was used, employing the [FOS](#) bubble sheet form. The process began with SUNY Binghamton who designed the layout of the FOS form. The [UBN-ICD](#) contracted with a translator to translate the survey, instructions, and introductory letter into Spanish. They then worked with Scantron to organize the printing of both the English and Spanish [FOS](#) documents. The UBN-ICD compiled and mailed out two sets of surveys to each of the 2265 families that were sampled from the KIDS [EIP](#) data system by the DOH. The completed forms were returned to the UBN-ICD from each family. The completed forms were sent to the [UB-PHO](#) via certified mail and were marked confidential.

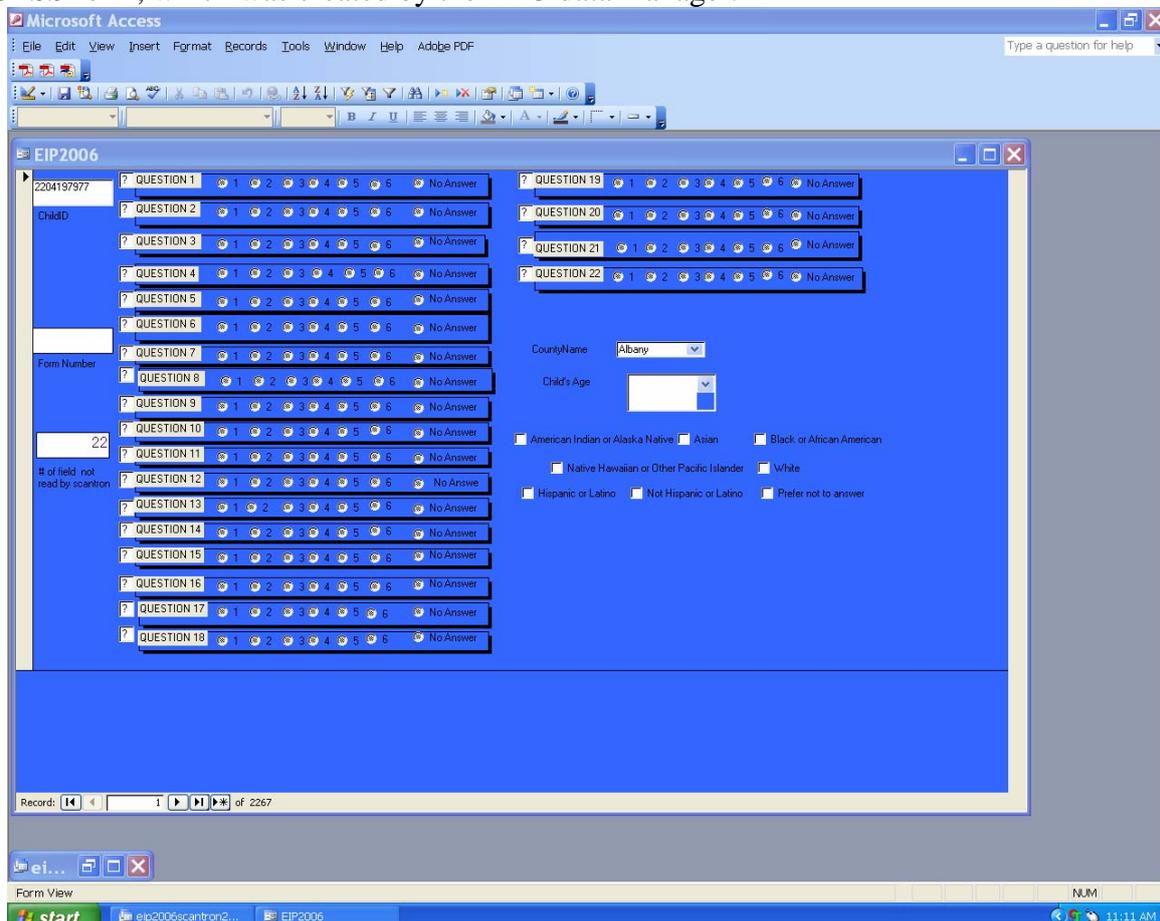
The UBN-ICD developed a website to provide training and education to parents who were filling out the forms. All of the forms produced were made available on the internet, in both English and Spanish. Links to the website were provided to county representatives so that they could assist

families in completing the form if necessary. 800 Number and Email Support Desks were operated for provide technical assistance and training to families completing the [Family Outcomes Survey](#). Questions asked were added to the [‘Frequently Asked Questions’](#) section on the website. Questions posed included: what if questions don’t reflect ways in which services were helpful to their child, what to do if child has not been receiving Early Intervention services for two years, and should they complete the survey based on Early Intervention services only or include information regarding their experience in Preschool Special Education.

Once the forms were received by the [UB-PHO](#) they were opened and sorted according to form number. When all forms were sorted they were put into one of five file folders according to their form number. For example one folder was labeled Forms 1-499 in which all forms with form number 1-499 were placed. The folder was also labeled with the date received. A batch cover sheet was then completed and placed in each file folder. The batch cover sheet accompanied the batched units at all times. The batched forms were then logged into the data entry log. When this was completed the file folders were put into a locked file cabinet inside a locked office until they were taken to the scantron machine, which transferred data to electronic form.

Data Entry

The data entry process for family outcomes began with [SUNY Buffalo’s](#) scantron machine. The batched forms were hand-carried to the machine and were never left unattended. When the forms had been scanned they were picked up along with a CD containing all data from the forms that were able to be scanned. The forms were then brought back to the Population Health Observatory ([PHO](#)), where the data were imported into a protected database for future handling. Each record in the database was then manually checked for errors with the aid of the following Microsoft ACCESS form, which was created by the PHO data manager.



Each record was loaded to the ACCESS form, which then provided summary information about missing values, while the data coordinator simultaneously viewed the original bubble sheet form. This allowed detection of common scantron malfunctions due, for example, to bubble sheets being filled out in ink. The data coordinator made changes deemed appropriate on the ACCESS form, which automatically recorded all changes made. The [PHO](#) data manager later reviewed the changes and made the final decision on whether to accept them. The ACCESS form also allowed for manual input of forms when necessary.

Filing System

The filing system of [Family Outcome forms](#) was an important aspect of this project. It was essential to ensure confidentiality and data integrity because each form had a designated location, which prevented forms being misplaced. The forms were organized in such a way that allowed for efficient access to each individual form. As previously stated the forms were organized and batched according to form numbers. The forms were then placed in file folders that were organized according to form numbers and dates received. [SUNY Buffalo](#) had access to a secure file which links the KIDS data system ID number to the designated form number. This allowed for easy access to each individual form when needed. If designated personnel had a need to locate a specific form they could supply the ID number from the KIDS data system and look up the matching form number and quickly locate the form. When the data from each form was entered the date of entry was recorded along with the archive date. [Family Outcome forms](#) were consistently kept in a locked file cabinet within a locked office when not in use.

Tracking Progress of Sampling

The [UB-PHO](#) Data Coordinator tracked the number of responses received, by municipality, and periodically reported progress toward filling out the planned samples to the [EIP](#) Director and staff. The last batch of forms was received from the [UBN-ICD](#) through January 1, 2007. A total of 580 families (25.6%) responded to the survey.

Child Outcomes

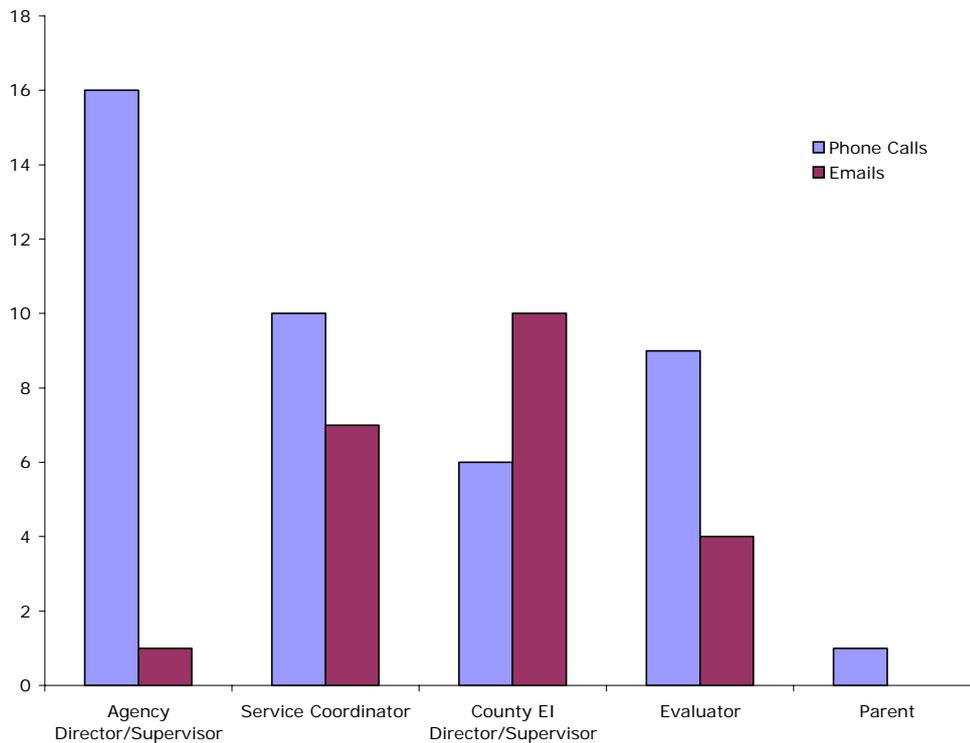
The process for handling and entry of child data from the COESF ([See Attachment B](#)) was developed. Exit form data will be handled and entered in the same way beginning with the collection of exit data as children in the 2006 entry sample (n=799) exit the program. The process, which is described below, also will be used to handle entry and exit data from subsequent cohorts, through that of 2010.

Data Collection

The [Child Outcomes Entry Summary Form](#) and [instructions](#) were created by the [NYS-DOH EIP](#) Director and staff in consultation with the [UB-PHO](#) and the [UBN-ICD](#). The UBN-ICD developed training and educational materials in collaboration with the NYS-DOH EIP Director and staff. Technical assistance and support materials were included. Three sets of materials were created; one for discussion facilitators, one for evaluators, and one for parents. Additionally, a simple introductory brochure was created to give to parents to explain the process. Colored folders were also created to facilitate county staff in identifying children in the sample. All materials were compiled into a reference binder. Each county was provided with a number of informational brochures, reference binders and child packets, which included a Discussion Facilitator Information Packet, a Evaluator Information Packet, a Parent Information Packet, and a colored folder (the specific number was dependent on the number of children in the sample for a particular county,

which was provided by the Department of Health). The UBN-ICD maintained a website to provide discussion facilitators, evaluators, providers, and parents easy access to these education and training materials. All of the forms produced, instructions, and the introductory letter were made available on the Internet. Additionally, the Parent Information Packet was translated into Spanish and was made available to county representatives and service coordinators to facilitate the completion of the Child Outcomes Summary Form with Spanish speaking families. The UBN-ICD operated 800 Number and Email help desks to assist stakeholders in completing the Child Outcomes Entry Summary Form. They received 42 phone calls and 22 emails regarding the Child Outcomes Survey (see the graph below for further break down of the type of people calling or emailing for information).

Figure 1
Telephone and Email Help Desk Activity, by Type of Stakeholder



Questions fielded by the help desks were added to the ‘Frequently Asked Questions’ section of the [UBN-ICD](#) Child Outcomes website. Questions posed included: where to locate specific forms and information, how evaluation and service coordination agencies would know if a child was included in the sample, when should the Child Outcomes Summary Form be completed and questions on how to complete the Developmental Milestones Checklist – Evaluator Edition.

A Focus Group was used to evaluate the utility of Child Outcomes Summary Form Technical Assistance support materials. One of the UBN-ICD staff members traveled to Nassau County to interview a focus group of county staff. The focus group was attended by approximately 14 staff members.

When the forms and instructions were ready to mail, the UB-PHO had a sufficient supply of copies made for the 58 counties/municipalities. The [UB-PHO](#) then sent each municipality an adequate number of forms for their required sample size in 2006 plus a few extra to make sure each had an ample supply. Local representative were reminded that training and educational materials and

answers to frequently asked questions were available at the [UBN-ICD](#) website and that email and telephone line help desks at the UBN-ICD could be accessed to obtain technical assistance if needed. Counties/municipalities mailed completed Early Childhood Entry Outcomes forms to the UB-PHO for data entry and processing. All municipalities were advised and reminded that the Child Outcome forms contain child identifying information and should be transmitted to the UB-PHO using confidential procedures that include the following:

1. Forms to be mailed should be sealed in an envelope and marked “CONFIDENTIAL”
2. The sealed envelope should be repackaged into a separate mailing envelope
3. The mailing envelope should be addressed to Amy Prescott who was authorized to receive and manage confidential data.
4. The envelope should be mailed using Registered U.S. Postal Service with return receipt requested.

Once the forms were received by the UB-PHO, they were immediately marked with the date received and put into a locked file cabinet inside a locked office for future data entry.

Data Entry

The data entry process for the Early Child Outcomes began when COESFs were received by the UB-PHO from the local municipalities. When the forms were received the transmitting municipality was immediately recorded in an Excel file, documenting receipt of the forms. The data were then entered manually via an ACCESS form and were imported into a protected database for future handling. The ACCESS form was created by the UB-PHO data manager in a way that allowed all data to be integrated into the form. This ACCESS form is shown below.

When the data from each original form were entered the date of entry was recorded along with the archive date. The original forms were then put into a locked file cabinet within a locked office for permanent archiving

Early Childhood Outcomes Data System, 2006 Annual Report

Microsoft Access - [Child Outcomes : Form]

File Edit View Insert Format Records Tools Window Help Adobe PDF

Tahoma 8

1.) Date Completed 0 0 2.) Child's Name 0 0 Eligibility 0

3.) Child's Date of Birth 12:00:00 AM 12:00:00 AM 4.) Child's Sex 0 County Code 0

6.) IFSP Team Members
 Parents 0 Evaluator(s) 0 EIO/D 0 Service Coordinator 0 Service Provider(s) 0 Other 0

7A.) Positive Social Emotional Skills 0 0

7B.) Acquire and Use Knowledge and Skills 0 0

7C.) Take Appropriate Action To Meet Needs 0 0

8A.) Social Emotional Skills Standardized Test 0 Criterion-Referenced Test 0 Clinical assessment 0 Evaluator Observer 0 Parent/Caregive Observation 0

8B.) Acquiring/Using Knowledge Standardized Test 0 Criterion-Referenced Test 0 Clinical assessment 0 Evaluator Observer 0 Parent/Caregive Observation 0

8C.) Taking Action to Meet Needs Standardized Test 0 Criterion-Referenced Test 0 Clinical assessment 0 Evaluator Observer 0 Parent/Caregive Observation 0

Outcome	Test Number	Name/Edition of Test
9A.) Social Emotional Skills	Test No. 0 0	
	Test No. 0 0	
	Test No. 0 0	0
	Test No. 0 0	
	Test No. 0 0	
9B.) Acquiring/Using Knowledge	Test No. 0 0	
	Test No. 0 0	
	Test No. 0 0	0
	Test No. 0 0	
	Test No. 0 0	
9C.) Taking Action to Meet Needs	Test No. 0 0	
	Test No. 0 0	
	Test No. 0 0	0
	Test No. 0 0	
	Test No. 0 0	

Record: 986 of 986

Form View

start Child Outcomes... Child Outcomes... Inbox - Micro... My Documents Report3.doc - M... Continue from a... Child Outcomes... 10:10 AM

Filing System

The filing system of Child Outcomes Entry Summary Forms also was an important aspect of this project. It is essential to ensure confidentiality and data integrity because each form has a designated location which prevents misplacement. The forms were organized in such a way that allowed for easy access to each individual form when needed. When a batch of forms was received by the [UB-PHO](#), the forms were recorded to a log in an Excel file with the date received, the number of forms received, the number of children found eligible and ineligible, along with documentation when a municipality completed their sample. The forms were then put into a designated folder. These file folders were labeled with the municipality's name and were stored alphabetically. Each form has a unique handwritten ID number on the back. This number was generated when data were inputted into the ACCESS form. This aided with organization and efficient tracking of forms.

Tracking Progress of Sampling

The UB-PHO Data Coordinator tracked the number of forms received from each municipality as they were received and periodically reported progress toward filling out the planned samples to the [EIP](#) Director and staff. As of June 27, 2007, her report contained the following information:

- 58/58 counties had submitted all or some forms
- 55 out of 58 municipalities had completed their sample
- A total of 1002 forms had been received
- Out of the 1002 forms:

- 884 (88.2%) were found to EIP eligible
- 93 (9.3%) were found not eligible
- 8 (0.8%) did not respond
- 1 (0.1%) could not be located
- 1 (0.1%) moved
- 15 (1.5%) refused services

Data Confidentiality and Security

The [UB-PHO](#) takes great care to protect the confidentiality and security of data, both before they are stored in the IT data management system and after. [The ECO Data System \(ECODS\) Security Protocol](#) contains information on the protection of security and confidentiality of data in the ECODS IT system. In this section, we present the policies and procedures followed before the data have been stored in the IT system, before and during the receipt and entry of data forms. The UB-PHO ECO Data System Security Protocol is a comprehensive document that provides a detailed description of policies and procedures to be followed by the PHO to ensure tight security of the ECO Data System and confidentiality of the ECO data. The Protocol is presented in its entirety in an attachment to this report ([See Attachment C](#)).

Pre-electronic handling of data

SUNY Buffalo has demonstrated extreme effort in making sure that all employees follow confidentiality procedures when working with the family or child outcomes data. Before data are entered into the IT data management system, the [UB-PHO](#) is responsible for making sure all forms are protected and kept secure. When the [FOS](#) forms are received from the [UBN-ICD](#) or when the [COESF](#) are received from municipalities, they are only possessed by authorized personnel. The FOS forms are then dropped off and picked up from the scantron services personally by authorized personnel. The forms are taken directly from the scantron machine back to the designated locked file cabinet inside a locked office. Likewise, COESFs are handled and processed only by authorized personnel. When these forms are received the data contained in them are immediately inputted. Then the forms are immediately stored in a locked file cabinet inside a locked office. All forms are kept under lock and key at all other times, except when being reviewed by authorized personnel. Forms are never left unattended when not in the locked file cabinet.

The PHO has designated Amy Prescott as its HIPAA/FERPA compliance officer. It is her responsibility to ensure that all employees are knowledgeable of HIPAA/FERPA rules and that data are handled in a compliant fashion.

Electronic handling of data

When data are entered it is done so in a very secure manner. Data are entered into a password protected program on designated password protected computers. Only authorized personnel have access to these computers. The computers are also kept in an inner locked/protected office.

HIPAA/FERPA Training

Each employee is required to, and has, participated in HIPAA compliance training. This training consisted of an online tutorial that can be found at <http://www.goer.state.ny.us/Train/onlinelearning/HIP/000.3.html>. Each employee was required to complete the “HIPAA Basics” portion of the tutorial. When the tutorial was completed each

employee printed out their certificates which are being kept under lock and key. Each employee is recertified annually. An example certificate of completion is shown below.



Each employee also attended a Power Point presentation by the HIPAA/FERPA officer on Tuesday 9/5/06. The HIPAA presentation addressed topics such as, purposes of HIPAA, protected health information, and rules of thumb when working with confidential data. The slides for this presentation have been included in [Attachment D](#) of this report.

Each employee also participated in a confidentiality training session given by Todd Gerber from the [New York State Department of Health](#) on Friday 10/6/06. The slides for this presentation are included in [Attachment E](#) to this report. The training consisted of the presentation of general FERPA rules, procedures and practices to prevent mistakes, and practices of safe data-handling procedures. After the training each employee signed a confidentiality agreement. The agreement has been attached to this report as [Attachment F](#).

This training process will repeat annually for current employees. In addition each new employee must complete the training before starting work. New employees also will be required to sign the confidentiality agreement and current employees will update their agreements annually.

[SUNY Buffalo](#) has not only provided substantial confidentiality training for employees, but also has made great efforts to follow confidentiality procedures on a day to day basis. For example, all [Family Outcome forms](#) are kept in a locked file cabinet inside a locked office. Periodic checks are made to make sure each employee is following the procedures, such as keeping computers facing away from windows and doors, keeping computers and all files password protected, making sure data are returned to its appropriate location after use, making sure all documents are shredded when

needed, and making sure data is not sent through email or transported electronically in unencrypted form.

As this project progresses SUNY Buffalo will be responsible for an abundance of confidential data. As a result, SUNY Buffalo will make sure each employee is staying on track as far as confidentiality compliance in the following ways:

- Each new employee will be required to complete the HIPAA tutorial
- Each year all employees will attend a HIPAA Presentation given by Amy Prescott
- Each year all employees will sign a confidentiality agreement
- Each year all employees will participate in Todd Gerber's confidentiality training
- Periodically each individual employee will be asked to state how they are following confidentiality procedures
- Offices and file cabinets will be checked periodically to make sure they are locked at all times
- Offices will be checked periodically to make sure they are restricted to authorized personnel only
- Computers will be periodically checked when not in use to be certain that the user is logging off
- All files will be checked to make sure they are being zipped, encrypted, password protected and stored in the appropriate place
- All necessary mailings of confidential information will be mailed via certified/return receipt
- A paper shredder will be easily accessible to all employees to ensure that documents are being shredded when disposed
- All employees will understand the importance of confidentiality and the consequences of not following procedures

Communications with Counties

SUNY Buffalo has developed lines of communication with the appropriate representative in each individual county. SUNY Buffalo has a complete list of phone numbers and email addresses of these representatives, which allows for communication whenever necessary. This list of contact information is included in the appendix of this report. Each of the 58 counties were called, when the [Child Outcomes Entry Summary Forms](#) were mailed out, to confirm that each county had received their forms and also allowed for the [PHO ECO project](#) data coordinator to introduce herself to each county representative and to ask if there were any questions at that point. Throughout the initial telephone call it was made clear to the county representative that questions about mailing and submission of [ECO forms](#) are encouraged and should be directed to Amy Prescott at SUNY Buffalo.

On Tuesday 11/21/2006 a follow-up email was sent to each county by SUNY Buffalo. The email consisted of a friendly reminder that SUNY Buffalo would like the forms to be sent in before the end of November. As of November 29th, 17 counties were in compliance with that request.

An excel file that contains records of all communications with each individual county to date was created. The date and time of each communication is recorded therein. The name of the individual along with a summary of the dialogue is recorded. This allows SUNY Buffalo ready access to important information about past conversations and emails with individual counties and to better understand the nature of each county's questions and concerns. We will continue to add

records to this file to document future communications. This file will be very beneficial to SUNY Buffalo in that it will help in knowing what directions may need to be clarified or what concerns should be addressed. The file is secure and is never looked at by unauthorized personnel.

DATA STORAGE, MANAGEMENT, AND PROCESSING

During the first year of the project (*i.e.*, 2006), the [UB-PHO](#) designed an IT system, planned for and hired the personnel to build and operate it, and purchased the hardware and software required to build data capacity for storing, managing, and processing family and child outcomes and related datasets. Minimum standards for the database design and management of [ECO](#) project data were defined. Databases for family and child outcomes were built according to these standards. In this section, we present the operating procedures that were adopted to ensure that well-organized, well-documented, and high quality data were (will be) provided by the Database Management System (DBMS) for processing and statistical analysis. We then describe the IT infrastructure to be built in the second year of the project to house these databases.

UB-PHO Standard Operating Procedures for ECO Database Management

The Standard Operating Procedures (SOP) presented in this section define the minimum standards of the database design and management for ECO project databases. The purpose of the ECO DBMS is to transfer data to the federal Office of Special Education Programs ([OSEP](#)) in compliance with requirement for New York State Performance Plan reporting, while assuring the confidentiality of the data involved, and providing high quality data for statistical analysis. The procedures discussed here were/are applied to all data managed and maintained at the UB-PHO for the ECO project.

Database Design

Database design is the responsibility of the database administrator (DBA) and programmer assigned to the ECO project. If more than one programmer is assigned to the project, the senior programmer is responsible for establishing the style and pattern of database design. Each programmer is responsible for maintaining consistency of database design throughout the lifespan of the ECO project. It is the responsibility of the senior (or supervising) programmer to ensure that an adequate and consistent design is maintained.

Components of Database Design: The [UB-PHO](#) DBMS design for [ECO](#) databases includes all of the following components. These components will be present in all future DBMS designs.

- Review of proposed work and forms
 - The DBA will be involved in reviewing the proposed work and data collection instruments prior to data collection in order to ensure that data received will be unambiguously interpretable and that the format is conducive to efficient and accurate data entry.
- Development of a data key (ID) system
 - The UB-PHO programmer assigned to building a database must establish a consistent subject identification system for all data in the ECODS data warehouse that allows linking of records for the same child at different times and linking of records between ECO databases and the KIDS system. This must be done in a way that guarantees that the KIDS system unique identifier is not contained in ECO datasets and that the associated ECO dataset identifier cannot be used to identify the child or family associated with it. Datasets that must be created for data analysis must be created by the

programmer and stripped of all identifying information before being served to the data analyst.

- Each piece of data collected for a given child (family) must be linkable to any other piece of information for that child or their family (family or their [EIP](#) participating children). That is the identifying system must ensure that each piece of data can be appropriately matched with other related pieces of data within the ECO data warehouse and to external data that will be used in the project (*e.g.*, data from the KIDS EIP system).
- Inventory, tracking, documentation files
 - An inventory list, including the in/out of datasets, dataset dictionaries, the form design, the programs associated with the creation and management of the datasets, and other supporting documents, must be kept for datasets in UB-PHO data warehouse. A PHO Dataset Documentation Form ([See Attachment G](#)) must be completed for each dataset created and stored in an easily identified folder for dataset documentation, both in the warehouse and off-line.
 - A record will be kept of the status of the ECO datasets, containing an overview of the data, completeness, and readiness for analysis is available for review.
 - Computerized files and scripts, containing standardized codes, will be kept against which all pieces of data will be checked for proper coding to ensure that ids, birth dates, gender, and other important information to be consistent across datasets.
- Directory structure and naming conventions
 - Individual datasets will be named to reflect the instrument they represent, and each version will have a unique, sequential name with year attached as a suffix.
 - Each dataset should have a related documentation file explaining what is stored therein, sources of original data, and documentation of programs used to produce the current dataset from source data.
- Data entry
 - Data arriving on paper forms will be double checked independently, electronically compared, and reconciled by a different person.
 - Data arriving in other formats should be processed using methods appropriate to the format in which it arrived.
- Creating/adding to a database
 - Unique filenames should be used to allow reconstruction of the database if ever necessary. If the original external data were received with the same file name, the file should be put into a separated directory with proper documentation, and the file renamed if there is potential confusion. The [ECO Family Survey](#) data are scanned by Scantron in UB and all named as 'Early Intervention Survey 2006.csv'. They will be stored in directories named by the date of scanning in the format of YYYYMMDD, such as ECO\scantrondata\20060918.
 - Check for initial data will be run as an initial step in creating a database for storage.

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- Error reports will be written to bring attention of the correspondent in the ECO project to any invalid or illogical responses. All corrections should be made until the data are clean. All changes will be documented with the original file submitted.
- An electronic comparison will be run comparing each version of a database to the previous version in order to check that all intended changes have been made and that no unintended changes have been made.
- A careful check of number of observations and number of variables will be made to assure that these are always as intended.
- All logs and outputs will be carefully examined for possible errors.
- Data verification
 - The DBA and the programmer will verify at least a portion of all newly computerized data against the original forms. For [ECO Family Survey](#) data, about 10% of returned forms will be taken and compare to the data in the database manually.
 - Additionally, the initial version of the database should be completely verified by correspondent and in the subsequent versions after cleaning and/or reconstruction, at least 10% of records will be verified by them.
- Documentation
 - A codebook and annotated data collection/entry/query form will be created to document each dataset. A hardcopy of the code book will be kept in the data coordinator's office for reference.
 - As stated above a PHO Dataset Documentation Form should be completed for each dataset entered or created in the data warehouse ([See Attachment G](#)).
 - Programs should be internally documented to include comments that explain what the program is doing.
- Supervision
 - New employees will be trained by example, by written and oral direction from supervisors/upper level programmers.
 - Supervisors and/or upper level programmers will thoroughly review all code written by new employees/junior programmers until satisfied with the accuracy of the code written.
 - Once satisfied with the accuracy of code written, supervisors/upper level programmers will still review a selection of programs written for accuracy.
- Confidentiality and security
 - Employees will sign a confidentiality pledge ([See Attachment F](#)).
 - All personnel must be firmly committed to the principle that the confidentiality of each individual data must be protected.
 - The access and management of databases must be in full compliance of the HIPAA and FERPA regulations.

Planned IT Infrastructure

Datasets created according to the standard operating procedures described above will be stored and managed in an IT system described in this section in future years. In year 1, the computer system was planned/designed to meet all [ECO](#) project needs and to allow flexibility in the future to expand capacity and capability. The hardware and software required to build the system was purchased at the end of the first year. Implementation of the design began in year 2 (2007).

During the first year of this MOU, the [UB-PHO](#) has completed a plan to develop data capacity to host highly confidential ECO data over an extended period of time, and to provide ready accessibility of the data to program administration and authorized county representatives. In addition to security and accessibility considerations, the planned ECO system meets the following requirements: The system provides (1) sufficient storage capacity, not only for the data itself, but also to host the database in which the data reside; (2) a development and testing environment that will produce a stable, reliable, user friendly, and expandable system; (3) management utilities that allow efficient operation of the system; (4), analysis programs such as SAS, and other accessory programs. The system will have systematic backup capacities (manual and automatic, onsite and offsite). The system and those operating it must be facile enough to provide reports regularly and on-the-fly when needed. The software system must be robust, flexible and extendable in anticipation of future growth. The details of these considerations have been captured in the various phases of development listed below.

Design Phase

In this phase, we evaluated several options for hardware infrastructures, operating systems, databases, development environments, and program designs. Mostly, the following setups had been thoroughly researched:

Solaris 10 / Sun servers – we had extensive experiences with this system, but the cost of the hardware was high and the cost of suitable software made the system even less affordable.

Linux / Intel based servers (IBM or DELL) – more cost effective for both hardware and software, but the lack of support was a concern. Also, the Linux operating system is not widely used in State government, which could cause unforeseeable compatibility issues when interacting with state agencies.

Microsoft windows server/PC servers (IBM or DELL) – We chose the MS server 2003 operating system on Dell PowerEdge servers as our hardware platform, as it is well established, widely used and of reasonable cost. However, extensibility and performance might be of concern when our system grows, and more demanding work is needed. These concerns will be addressed when, and if, necessary.

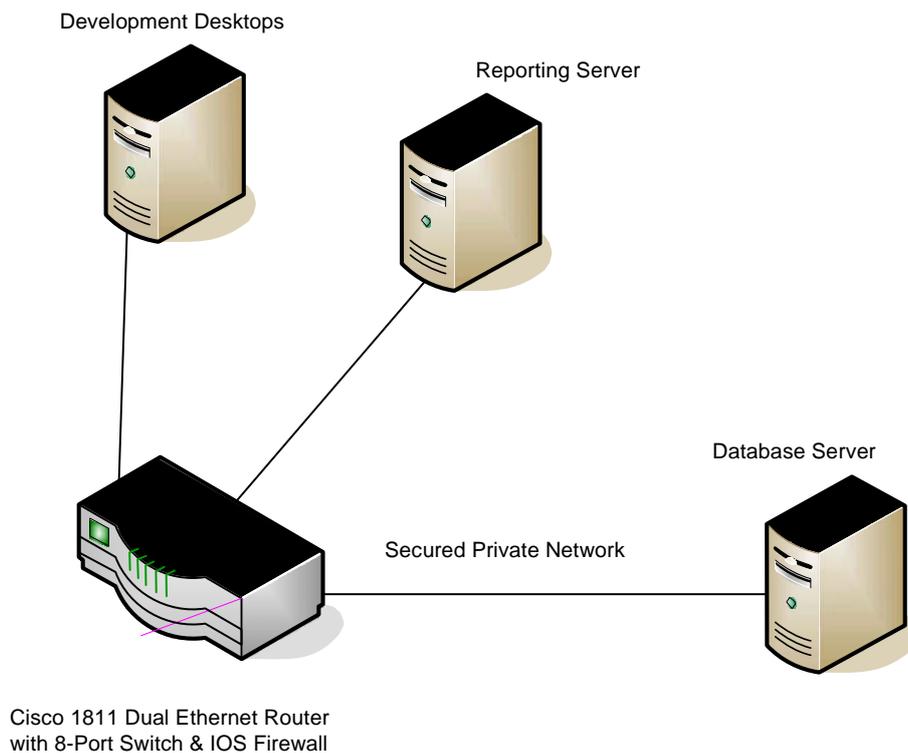
We had evaluated several database solutions for the ECO project. Oracle was the most powerful and extendable system considered. It is widely used in enterprise and research settings. However, it is very complicated and heavy-duty for our project. It is also the most expensive solution considered. MySQL is very cost effective, widely used in smaller business and higher education institutions, with enough capabilities for our needs, but it suffers from disadvantages similar to those of the Linux system mentioned above. Microsoft SQL Server was the chosen database management system solution and will be implemented when our system is fully setup. It was relatively cost effective, widely used by government agencies, rich resources on helps and documentations, and relatively easy to manage. Until the system is fully functional we are using Microsoft ACCESS. The limitation of using ACCESS is apparent. It lacks some crucial advanced features needed, such as detailed audit trail, roll-back capacity, advanced user access control, full

multiple user accessibility, etc. The ACCESS database, however, is very light weight and easy to implement. In the interests of expediency while we are implementing the Microsoft SQL Server solution, we are hosting our current data in it. It is quite adequate for current purposes. More details on the plan to develop the final system are discussed in the implementation section below.

We use the SAS programming system for data management and analysis. SAS is the industrial standard on these tasks and we have a high level of expertise and experience with it. We use various productivity software products, such as Microsoft Office, Paint.Net, PowerPoint, and Latex for reporting and presentations. We chose Microsoft Visual Studio as our standard development environment. Eclipse and DreamWeaver are also used for different programming tasks. We will utilize a version control system (Subversion) for source code and documentation management when the full system is setup. Other utility software such as WinZip is also used in the project.

After the initial evaluation, we researched several vendors for the hardware and software. We developed a budget and revised it several times in response to communications with state agencies on policies and security requirements.

The system to be developed is illustrated schematically below



The security of the system is a top priority. In addition to highly reputable build-in firewalls in the Cisco router, we have evaluated several software firewall solutions from Microsoft, Norton, ZoneAlarm, BlackIce and others. We decided to use BlackIce, due to its flexibility, strong record, and wide use in our University (support is readily available). Given this combination of hardware and software, combined with the utilization of Microsoft Baseline Security Analyzer (MBSA), the system will be robustly protected.

Implementation Phase

Detailed hardware setup plans are detailed in the ECODS Security Protocol in [Attachment C](#). Please refer to that document for more detailed information about the planned hardware setup. For programming, we are using Access database for table design and form design, SAS for database management, and SAS and R for statistical programming.

Previous sections of this report detailed our procedures for handling data in paper form. We utilized the Scantron service on UB campus to scan the [family outcomes forms](#) and turn them to comma separated computer text files. Child data was entered manually from [child outcomes forms](#).

The data obtained by Scantron were imported to an ACCESS database through SAS scripts. We programmed the importing of data through SAS, and not the more straightforward method of importing from an ACCESS database, because we wanted to be able to re-construct the database when needed. This is a very important design principle that we employed to safeguard against an unexpected loss of a database. The SAS program and its log serve as documentation on the structure of the tables in the database. This approach also gives us very detailed information on the data, part of the data status report, for example, was based on the results obtained through these programs. In addition to the raw data, several accessory tables such as the county FIPS codes and children's age codes are also imported to the database through SAS scripts.

It should be noted that the only objects in the ACCESS database that can be created by SAS programs are the tables; all other objects such as forms and modules have to be created in ACCESS. We created forms that reassemble the actual paper form in the database. The ACCESS form was used to manually inspect and input the data. The similarity between the paper form and ACCESS form reduced error and increased data input efficiency. By programming with modules in the database, the form also recorded the date automatically in the table if any changes were made to the record and, therefore, provides information on changes to the database. This greatly reduced the possibility of modifying records by accident, because any such changes can be easily detected and checked out.

Because the Scantron service did not recognize all forms (mostly because the form was not filled in properly), every form was manually compared with the records in the database. All missing values were filled in and errors were corrected. Since Scantron data entry is an error prone process, these precautions were important to reduce mistakes. As mentioned above, ACCESS forms were designed to aid the data entry and reduce stress. Also, completed data forms were selected at random and compared with the data in the database. SAS programs were written to check for outliers in the database as an additional way to catch possible errors.

DATA SUMMARIES AND ANALYSES

During the first year of the project, we successfully achieved our primary goal to create family and child outcomes databases to transfer to the [OSEP](#) and to summarize and analyze for the [SPP](#). The datasets were transferred to OSEP, via CD through the [EIP](#) Director, on January 9, 2007. The CD included data encrypted family and child data files with records received on or before December 31, 2006, database descriptions, and notes files. The 2006 datasets were updated later to include all data received as of January 11, 2007 (Family data) and July 1st, 2007 (Child data). The summaries and analyses in this report are based on the updated datasets.

Family Outcomes Data Analyses

The 580 families of current participants in the EIP who were sampled and who returned completed [FOS](#) forms comprised the sample of families in this study. This included an over-sampling of New York City to produce a large enough locally representative sample for a separate analysis for that municipality.

Sample Description

A description of the sample of 580 families who responded to the FOS is presented in Table 6.

Table 6³
 Characteristics of children whose families responded to the family survey

Race	N (%)	Family Language	N (%)	Eligibility Category	N (%)	Length of Stay in the EIP	N (%)
American Indian-Native	2 0.34	Chinese	6 1.17	Delay in One Area	128 26.55	Up to 1 Year	220 37.93
Asian	34 13.37	English	381 74.56	Delay in Two Areas	344 59.31	1.5 Years	167 28.79
Black	57 7.42	Spanish	97 18.98	Diagnosed Condition	82 14.14	Up to 2 Years	81 13.97
Hispanic	82 14.14	French	1 0.20			Up to 3 Years	101 16.50
White	322 55.52	Thai	1 0.20			More than 3 Years	11 1.9
Missing	83 14.31	Other	20 4.2				
		Unknown	5 0.98				

Age at Referral	Percent (N)	Age at Exit	Percent (N)	Sex	Percent (N)
0-12 mos	20.34%(118)	0-12 mos	.52% (3)	M	68% (397)
13-24 mos	41.21%(239)	13-24 mos	3.62%(21)	F	32% (183)
25-36 mos	38.45% (223)	25-36 mos	49.83%(289)		
		>36 Mos	46.03% (267)		

³ Table 3 was produced by the EIP Director and staff using information from the KIDS EIP database and was reported in the 2005-06 SPP. We have taken the numbers and percentages in this table from the corresponding table on page 42 of the SPP.

There appears to be a slight overrepresentation of Asians and under-representation of Blacks in the sample. It is unclear whether this reflects the population of children in [EIP](#) or is due to differing response rates to the [FOS](#) among races. To gain further insight, the current sample percentages should be compared to the corresponding percentages of participants in the EIP program and to those in the population as a whole.

Results of Statistical Analyses of Statewide Sample

Preliminary analyses indicated that the entire sample of 580 families was not biased by the over sampling from NYC. Thus, we present statewide results in this report for the entire sample, including the extra samples gathered in NYC.

Rausch model analysis was applied to the data for the 22 items of the FOS form to obtain a “satisfaction score” for each of the 580 families in the statewide sample. The WINSTEPS program was used to estimate family effects (*i.e.*, *family scores*) for each family and item scores for each item.

The family scores from the Rausch model analysis were compared to threshold values to obtain the percentage of families who were satisfied with each of the key items designated for analysis in the 2005-06 State Performance Plan. The threshold values were determined by the National Center of Special Education Accountability Monitoring ([NCSEAM](#)) from a sample of 1750 families from eight states. Under the assumption that a family is satisfied with an aspect of the program on which satisfaction is more easily attained if they are satisfied with an aspect on which it is more difficult to attain satisfaction, it is possible to estimate the percentage of families who are satisfied with any given aspect by calculating the percentage of family scores that exceed the threshold for the given item. The key items of interest, ordered from easiest to most difficult, and their corresponding thresholds were: Item 20, 516; Item 19, 539; and Item 17, 556. If a family’s score was greater than 539, for example, then the family was “satisfied” that participation in the program had helped them know their rights about EIP services. Table 7 shows the percentage of responding families whose level of satisfaction with the program exceeded each of the thresholds for each of these key items.

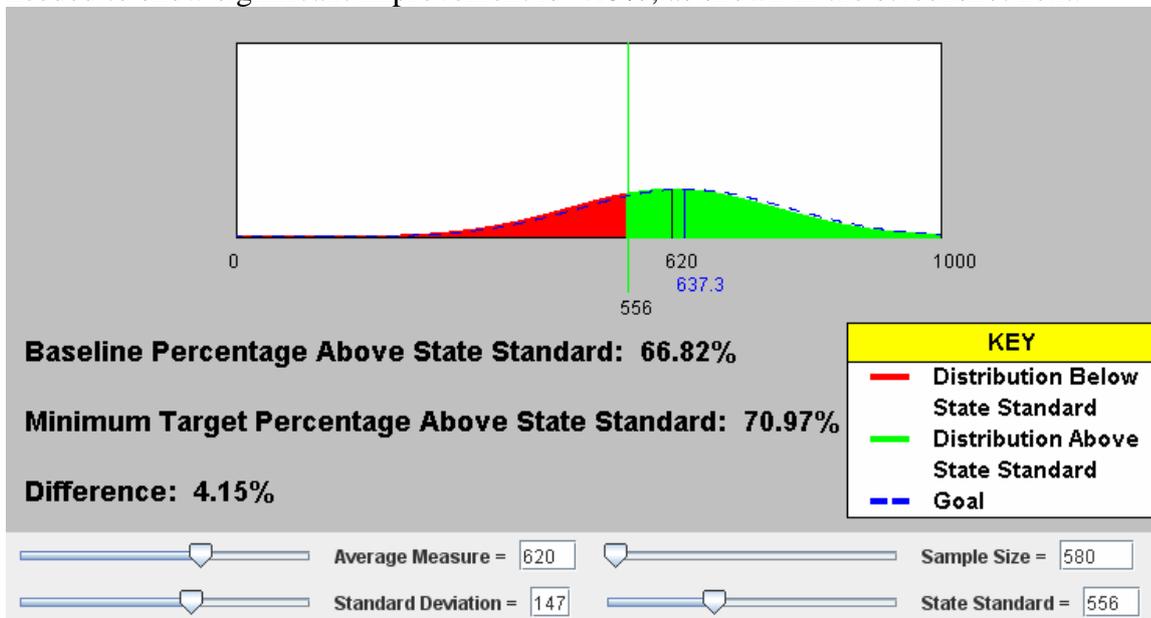
Table 7

Percentage of Families Satisfied with Three Items 17, 19, or 20 on the Family Outcomes Survey (n=580, Statewide Sample)		
Item Number and Description	Percentage above Threshold	95% Confidence Interval
Item 17 (Threshold Score = 556) EIP services have helped me and/or my family communicate more effectively with the people who work with my child and family	65.7	(61.8, 69.6)
Item 19 (Threshold Score = 539) EIP services have helped me and/or my family know about my child’s and family’s rights concerning EIP services	71.7	(68.1, 75.4)
Item 20 (Threshold Score = 516) EIP services have helped me and/or my family do things with and for my child that are good for	82.4	(79.3, 85.5)

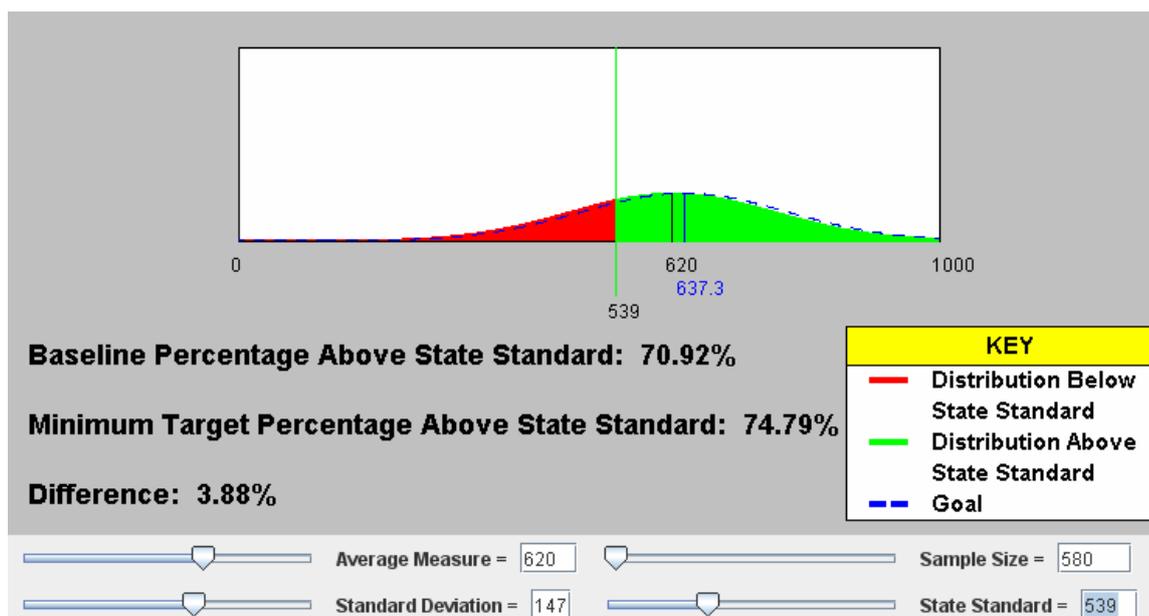
my child's development.		
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Targets for improvement were obtained from the [NCSEAM Calculator](#). Assuming that family scores are normally distributed with mean equal to the sample mean in our study (620) and standard deviation equal to our sample standard deviation (147). The calculator determines the increase in average family scores in a new sample of 580 families that would be required to be a statistically significant increase from the baseline mean of 620. The calculated increase was 17.3. That is, next year we would have to observe a mean of 637.3 to declare significant improvement in family scores. Such a shift in the Gaussian distribution (from 620 to 637.3) would produce expected increases of 3.50% above the threshold for item 20, 3.88% above the threshold for Item 19, and 4.14% above the threshold for Item 17. The calculations that produced these target increases are illustrated below for Items 17, 19, and 20, respectively.

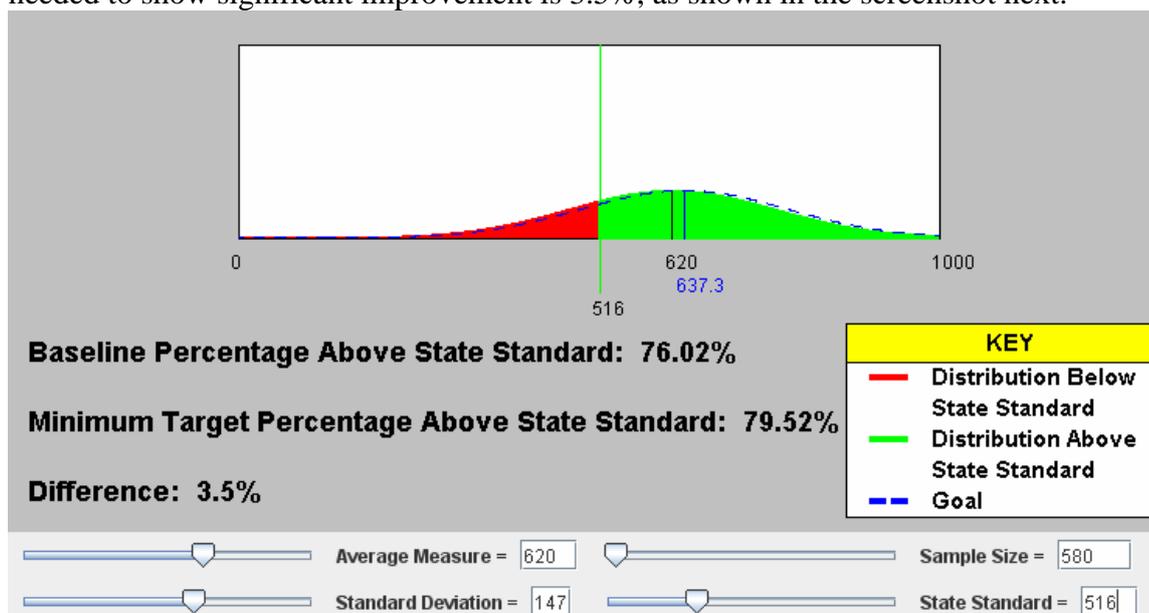
Item 17 (Indicator 4b in the SPP): Threshold = 556, and the calculated percentage difference needed to show significant improvement is 4.15%, as shown in the screenshot next.



Item 19 (Indicator 4a in the SPP): Threshold = 539, and the calculated percentage difference needed to show significant improvement is 3.88%, as shown in the screenshot next.



Item 20 (Indicator 4c in the SPP): state standard = 516, and the calculated percentage difference needed to show significant improvement is 3.5%, as shown in the screenshot next.



To achieve these targets the [EIP](#) program will have to improve the percentages of family scores above the corresponding thresholds for Items 17, 19, and 20 to 69.8, 75.6, and 85.9, respectively.

Overall, the average score for the 580 families sampled was 620 with a standard deviation of 147. This score falls between the thresholds for the fourth and fifth most difficult items on the [FOS](#). This means that the average New York State family was “satisfied” with all but four of the 22 items (Items 1, 2, 5, and 8). Improvement in the program, therefore, can be achieved by helping families to: Participate in typical activities for children and families in their community (Item 1); improve their quality of life (Item 2); know where to go for support to meet their needs (Item 5); and keep up friendships for their child and family (Item 8). The results in this section provide a baseline from which to measure improvement in future years.

Results of Statistical Analyses of New York City Sample

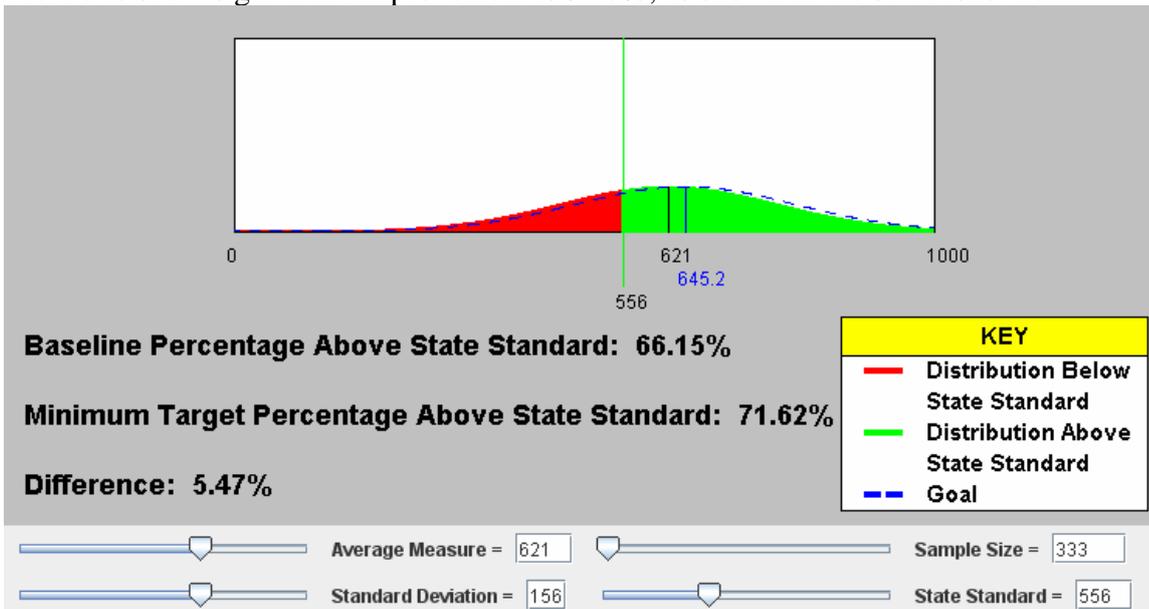
Through over-sampling of NYC Counties, a representative sample was obtained (n=333) to perform a local analysis of data from that municipality. The statewide analyses described above were repeated for NYC.

Table 8

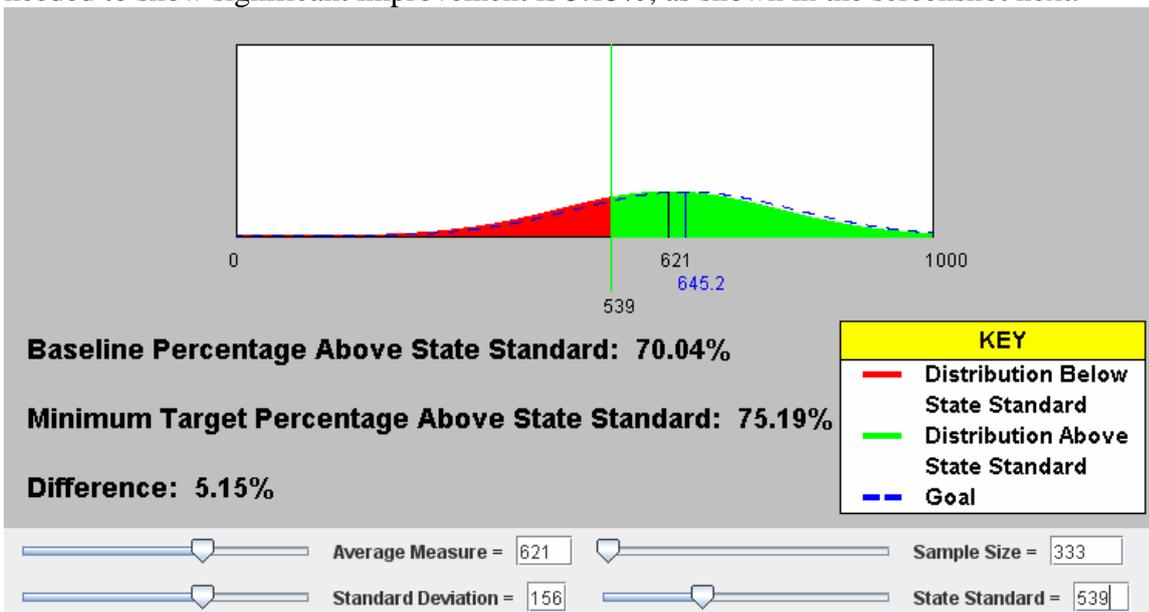
Percentage of Families Satisfied with Three Items 17, 19, or 20 on the Family Outcomes Survey (n=333, New York City Sample)		
Item Number and Description	Percentage above Threshold	95% Confidence Interval
Item 17 (Threshold Score = 556) EIP services have helped me and/or my family communicate more effectively with the people who work with my child and family	65.2	(60.1, 70.3)
Item 19 (Threshold Score = 539) EIP services have helped me and/or my family know about my child's and family's rights concerning EIP services	70.6	(65.7, 75.5)
Item 20 (Threshold Score = 516) EIP services have helped me and/or my family do things with and for my child that are good for my child's development.	82.6	(78.5, 86.7)

The overall mean family score was 621 with a standard deviation of 156. Targeted increases for next year were calculated using the [NCSEAM calculator](#) as above for the statewide sample. The results are illustrated below for Items 17, 19, and 20, respectively.

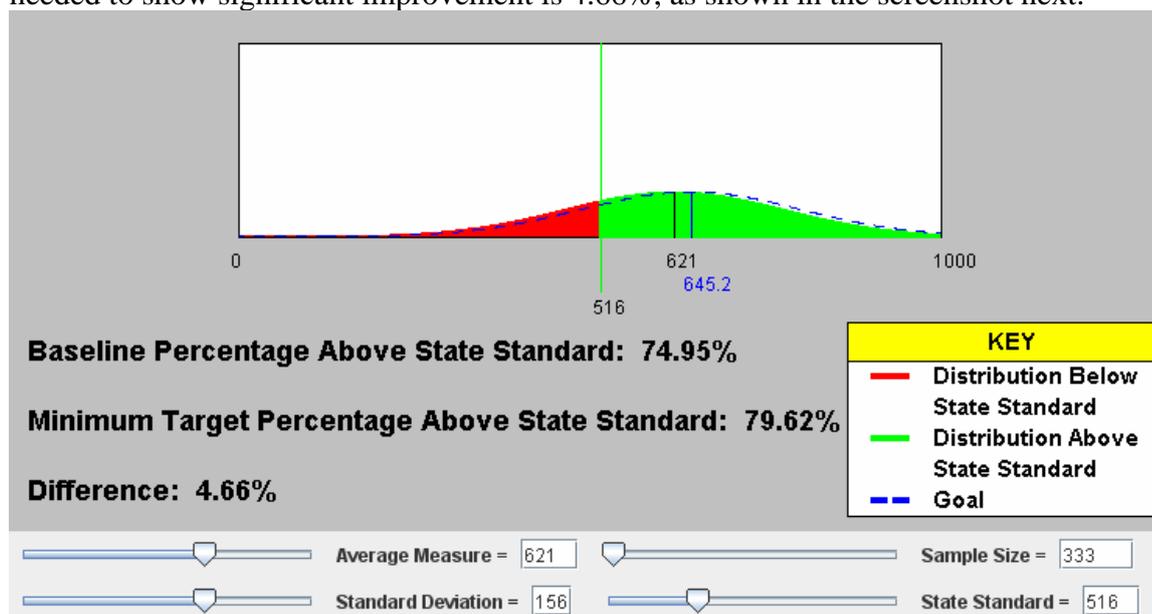
Item 17 (Indicator 4b in the SPP): Threshold = 556, and the calculated percentage difference needed to show significant improvement is 5.47%, as shown in the screenshot next.



Item 19 (Indicator 4a in the SPP): Threshold = 539, and the calculated percentage difference needed to show significant improvement is 5.15%, as shown in the screenshot next.



Item 20 (Indicator 4c in the SPP): Threshold = 516, and the calculated percentage difference needed to show significant improvement is 4.66%, as shown in the screenshot next.



Thus, the target percentages above the respective thresholds that NYC would have to achieve in order to show statistically significant improvement for Items 17, 19, and 20 are 70.7, 75.7, and 87.3%, respectively.

Child Outcomes Data Summary

The statewide sampling plan of the [SPP](#) originally called for a geographically proportional sampling of 800 children, newly evaluated by the [EIP](#) from September through November of 2006, with outcomes to be reported using the Child Outcomes Entry Summary Form ([COESF](#)). This number was reduced by one, due to special circumstances in Hamilton County. Thus a roughly proportional sample of n=799 children from geographic strata were targeted by the SPP's statewide sampling plan. Of these, 383 sampled from New York City (NYC) and 416 from the rest of the state. As of July 1st, 2006, 179 child data forms had been received from NYC (47%) and all 416 had been received from the other municipalities (100%), for an overall sample of 595 and response rate of 74.5%. Additional samples of 635 EIP participants in Nassau County and 635 in Suffolk County were planned for more in depth local evaluation of the EIP program. Child survey forms were completed for 253 and 154 of these over-sampled children (40% and 24%), respectively. Thus, the [UB-PHO](#) received COESF's for a total of 1002 (416+179+253+154) of the 2069 (416+383+635+635) children (48%) who were targeted for the statewide or local samples. Of the 1002 children for whom COESFs were returned, 884 were known to be eligible for EIP services. The forms for two of these were missing information on all of the child outcomes of interest. Hence, these two were deleted, leaving 882 children who were known to be EIP eligible. Of these, 485 were in the geographically proportional statewide sample, while 154 and 243 additional children were included in the locally representative samples for Suffolk and Nassau Counties, respectively.

Statewide Sample Summary

In this report, the geographically proportional statewide sample was combined with the extra samples from Nassau and Suffolk Counties to obtain one dataset of children who were known to be

eligible for EIP services. Tables presented in this section provide summaries of the entire sample of 882 eligible children. Results for only the 485 eligible children, in the geographically proportional statewide sample, were similar to those for the entire sample of 882. Thus, the larger dataset will be used to obtain baseline summaries of child outcomes that will be compared in future years to the same summaries statistics obtained when these 882 children leave the EIP. Tables 9-11 present the distributions of this sample by age at entry into EIP, gender, and municipality/county.

Table 9

Distribution of Statewide Sample of New Entries to EIP in 2006 by Age at Entry (n = 882)

age	Frequency	Percent	Cumulative Frequency	Cumulative Percent
<1	188	21.74	188	21.73
1	332	38.38	520	60.12
2	343	39.65	863	99.77
3	1	0.12	864	99.88
4	1	0.12	865	100.00

Frequency Missing = 17

Table 10

Distribution of Statewide Sample of New Entries to EIP in 2006 by Gender (n = 882)

Category	Number	Percent
Male	553	62.7
Female	310	35.2
No Response	19	2.1

Table 11

Distribution of Statewide Sample of New Entries to EIP in 2006 by Municipality (n = 882)

Distribution by Municipality/County				
County	Frequency	Percent	Cumulative Frequency	Cumulative Percent
ALBANY	4	0.45	4	0.45
ALLEGANY	2	0.23	6	0.68
BROOME	4	0.45	10	1.13
CATTARAUGUS	1	0.11	11	1.25
CAYUGA	2	0.23	13	1.47
CHAUTAUQUA	2	0.23	15	1.70
CHEMUNG	2	0.23	17	1.93
CHENANGO	1	0.11	18	2.04
CLINTON	2	0.23	20	2.27
COLUMBIA	2	0.23	22	2.49
CORTLAND	2	0.23	24	2.72
DELAWARE	2	0.23	26	2.95
DUTCHESS	5	0.57	31	3.51
ERIE	15	1.70	46	5.22
ESSEX	2	0.23	48	5.44
FRANKLIN	3	0.34	51	5.78
FULTON	2	0.23	53	6.01
GENESEE	2	0.23	55	6.24
GREENE	3	0.34	58	6.58
HAMILTON	2	0.23	60	6.80
HERKIMER	3	0.34	63	7.14
JEFFERSON	3	0.34	66	7.48
LEWIS	2	0.23	68	7.71
LIVINGSTON	3	0.34	71	8.05
MONROE	15	1.70	86	9.75
MONTGOMERY	3	0.34	89	10.09

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NASSAU	294	33.33	383	43.42
NEW YORK	179	20.29	562	63.72
NIAGARA	5	0.57	567	64.29
ONEIDA	4	0.45	571	64.74
ONONDAGA	3	0.34	574	65.08
ONTARIO	1	0.11	575	65.19
ORANGE	7	0.79	582	65.99
ORLEANS	2	0.23	584	66.21
OSWEGO	2	0.23	586	66.44
OTSEGO	1	0.11	587	66.55
RENSSELAER	3	0.34	590	66.89
ROCKLAND	11	1.25	601	68.14
ST LAWRENCE	1	0.11	602	68.25
SARATOGA	3	0.34	605	68.59
SCHENECTADY	2	0.23	607	68.82
SCHOHARIE	2	0.23	609	69.05
SCHUYLER	2	0.23	611	69.27
SENECA	3	0.34	614	69.61
STEUBEN	1	0.11	615	69.73
SUFFOLK	207	23.47	822	93.20
SULLIVAN	2	0.23	824	93.42
TIOGA	2	0.23	826	93.65
TOMPKINS	2	0.23	828	93.88
ULSTER	3	0.34	831	94.22
WARREN	3	0.34	834	94.56
WASHINGTON	2	0.23	836	94.78
WAYNE	3	0.34	839	95.12
WESTCHESTER	39	4.42	878	99.55
WYOMING	3	0.34	881	99.89
YATES	1	0.11	882	100.00

Table 12 (Item 6)
Distribution of New Entries by IFSP Team Makeup (Item 6)

	Frequency	Percent	Cumulative Frequency	Cumulative Percent
No Response	21	2.38	21	2.38
Parent(s)	3	0.34	24	2.72
Evaluator(s)	5	0.57	29	3.29
Parent(s)+Evaluator(s)	11	1.25	40	4.54
EIO/D	10	1.13	50	5.67
Parent(s)+EIO/D	12	1.36	62	7.03
Evaluator(s)+EIO/D	6	0.68	68	7.71
Parent(s)+Evaluator(s)+EIO/D	259	29.37	327	37.07
ServiceCoordinator	2	0.23	329	37.30
Parent(s)+ServiceCoordinator	2	0.23	331	37.53
Parent(s)+Evaluator(s)+ServiceCoordinator	73	8.28	404	45.80
EIO/D+ServiceCoordinator	2	0.23	406	46.03
Parent(s)+EIO/D+ServiceCoordinator	24	2.72	430	48.75
Evaluator(s)+EIO/D+ServiceCoordinator	6	0.68	436	49.43
Parent(s)+Evaluator(s)+EIO/D+ServiceCoordinator	395	44.78	831	94.22
Parent(s)+EIO/D+ServiceProvider(s)	3	0.34	834	94.56
Evaluator(s)+EIO/D+ServiceProvider(s)	1	0.11	835	94.67
Parent(s)+Evaluator(s)+EIO/D+ServiceProvider(s)	7	0.79	842	95.46
Parent(s)+Evaluator(s)+ServiceCoordinator+ServiceProvider(s)	4	0.45	846	95.92
EIO/D+ServiceCoordinator+ServiceProvider(s)	1	0.11	847	96.03
Parent(s)+EIO/D+ServiceCoordinator+ServiceProvider(s)	1	0.11	848	96.15
Evaluator(s)+EIO/D+ServiceCoordinator+ServiceProvider(s)	3	0.34	851	96.49
Parent(s)+Evaluator(s)+EIO/D+ServiceCoordinator+ServiceProvider(s)	31	3.51	882	100.00

Items 7A, 7B, and 7C of the [COESF](#) were designated by the [EIP](#) Director as key items on which to base an evaluation of the program. Baseline results for these items are presented, as percentage of responses in the category 6 or 7 versus categories 1-5, in Table 13. Note that there was one missing response for Item 7C.

Table 13 (Item 7)

Key Child Outcomes for EIP Eligible Children in the Entire Statewide Sample for 2006				
Baseline Data from 2005-06 Child Outcomes Entry Summary Form (COSF)				
Total N = 882	Children Functioning at Level <i>Comparable</i> to Same-Age Peers (Rating of 6-7 on COSF item) at Entry to the EIP		Children Functioning at Level <i>Below Same-Age</i> Peers (Rating of 1-5 on the COSF item) at Entry to the EIP	
	Percent	N	Percent	N
7A: Positive social-emotional skills (including social relationships)	42%	371	58%	511
7B: Acquisition and use of knowledge and skills (including early language /communication)	25%	218	75%	664
7C: Use of appropriate behaviors to meet their needs.	20%	176	80%	705

The children in the sample of 799 new enrollees to the EIP in 2006 will be tracked until they exit the program, at which time an exit survey form will be submitted and added to the ECO Data System's database. The comparison of exit to entry data for the children in this sample will be made in subsequent years of the project to evaluate whether the program services improve outcomes.

The responses to Item 7 are summarized by all seven scoring categories in Table 13.

Table 13 (Item 7)

Distribution of Sample into Scoring Categories

Positive Emotional Skills				
Category	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	32	3.63	32	3.63
2	82	9.3	114	12.93
3	138	15.65	252	28.57
4	96	10.88	348	39.46
5	163	18.48	511	57.94
6	174	19.73	685	77.66
7	197	22.34	882	100

Acquire and Use Knowledge				
Category	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1	49	5.56	49	5.56
2	142	16.1	191	21.66
3	206	23.36	397	45.01
4	129	14.63	526	59.64
5	138	15.65	664	75.28
6	121	13.72	785	89
7	97	11	882	100

Take Action to Meet Needs				
Missing	1	0.11	1	0.11
1	65	7.37	66	7.48
2	142	16.1	208	23.58
3	204	23.13	412	46.71
4	113	12.81	525	59.52
5	181	20.52	706	80.05
6	120	13.61	826	93.65
7	56	6.35	882	100

Table 14
Spearman Correlations Among Three Outcomes of Item 7

Spearman Correlation Coefficients Prob > r under H0: Rho=0 Number of Observations			
	q7a	q7b	q7c
q7a Positive Emotional Skills	1.00000 882	0.57836 <.0001 882	0.39434 <.0001 881
q7b Acquire and Use Knowledge	0.57836 <.0001 882	1.00000 882	0.50683 <.0001 881
q7c Take Action to Meet Needs	0.39434 <.0001 881	0.50683 <.0001 881	1.00000 881

Table 15 (Item 8)

Number and Percent of Children for Whom the Various Types of Supporting Evidence Was Used by IFSP Team to Determine Item 7 Outcomes

Type of Evidence	Item 7A	Item 7B	Item 7C
Standardized Test Score	735 83.3	765 86.7	754 85.5
Criterion-Referenced Test Score	454 51.5	455 51.6	424 48.1
Clinical Assessment	602 68.3	599 67.9	588 66.7
Evaluator(s) Observation	768 87.1	765 86.7	759 86.1
Parent/Caregiver Observation	760 86.2	744 84.4	741 84.0

Responses to Item 9 are not easily summarized, because they often were written in by respondents who did not bother to look up the test number on the instructions sheet that came with the

questionnaire. In the second year of the project we made associations of most of the responses that were written in with a test on the list and will report re-categorized responses in the 2007 report.

Local Sample Summaries

Over-sampling of Nassau and Suffolk Counties in 2006 allow for the calculation of local baseline percentages of responses to the child outcomes of primary interest (*i.e.*, Items 7A, 7B, and 7C) for these counties. The summaries are presented in Table 16 for Nassau County and Table 17 for Suffolk County.

Table 16 (Item 7)

Key Child Outcomes for EIP Eligible Children in the Nassua County Sample for 2006				
Baseline Data from 2005-06 Child Outcomes Entry Summary Form (COSF)				
Total N = 294	Children Functioning at Level <i>Comparable to Same-Age Peers</i> (Rating of 6-7 on COSF item) at Entry to the EIP		Children Functioning at Level <i>Below Same-Age Peers</i> (Rating of 1-5 on the COSF item) at Entry to the EIP	
	Percent	N	Percent	N
7A: Positive social-emotional skills (including social relationships)	43%	125	57%	169
7B: Acquisition and use of knowledge and skills (including early language /communication)	23%	69	77%	225
7C: Use of appropriate behaviors to meet their needs.	15%	45	85%	249

Table 17 (Item 7)

Key Child Outcomes for EIP Eligible Children in the Suffolk County Sample for 2006				
Baseline Data from 2005-06 Child Outcomes Entry Summary Form (COSF)				
Total N = 207	Children Functioning at Level <i>Comparable to Same-Age Peers</i> (Rating of 6-7 on COSF item) at <i>Entry to the EIP</i>		Children Functioning at Level <i>Below Same-Age Peers</i> (Rating of 1-5 on the COSF item) at <i>Entry to the EIP</i>	
	Percent	N	Percent	N
7A: Positive social-emotional skills (including social relationships)	40%	82	60%	125
7B: Acquisition and use of knowledge and skills (including early language /communication)	24%	49	76%	158
7C: Use of appropriate behaviors to meet their needs.	22%	44	78%	162

These results will serve as baselines for comparison to the corresponding percentages calculated from the exit data for these same children.

DISCUSSION

The State [EIP](#) is doing quite well with regard to the satisfaction level of families with participating children. The targets that have been set for improvement in the key family outcomes (Items 17, 19, 20 of the [FOS](#) form) may be difficult to achieve and, perhaps less important to achieve than improved child outcomes. Improvement in child outcomes may be even more difficult to achieve, if the disabilities of participating children are not sensitive to interventions. Nevertheless, the child outcomes data does reveal dimensions where improvement is most need and, perhaps most achievable. Only 20 and 25% of the children in our sample of newly entering eligible children in 2006 scored a 6 or 7 on the “Use of Appropriate Behaviors to Meet Their Needs” and “Acquisition and Use of Knowledge and Skills” dimensions. Modifications to the current interventions or the development of new interventions to specifically address these problems should be considered. There is also much room for improvement on the “Positive Social-Emotional Skills” dimension, although 42% of the children scored a 6 or 7 on this item.

ATTACHMENT A: Family Outcomes Survey Form

**New York State Department of Health
Early Intervention Family Outcomes Survey**

This is a survey for families exiting or who have recently exited Early Intervention services. Your responses will help guide efforts to improve services and results for children and families. For each statement below, please select one of the following response choices: very strongly disagree, strongly disagree, disagree, agree, strongly agree. You may skip any item that you feel does not apply to your family.



Please use pencil or pen. Fill in circle completely. Invariant 05 06

Very Strongly Disagree
Strongly Disagree
Disagree
Agree
Strongly Agree
Very Strongly Agree

Impact of Early Intervention Services on Your Family	
Over the past year, Early Intervention services have helped me and/or my family:	
1. participate in typical activities for children and families in my community.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
2. know about services in the community.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
3. improve my family's quality of life.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
4. know where to go for support to meet my child's needs.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
5. know where to go for support to meet my family's needs.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
6. got the services that my child and family need.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
7. feel more confident in my skills as a parent.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
8. keep up friendships for my child and family.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
9. make changes in family routines that will benefit my child with special needs.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
10. be more effective in managing my child's behavior.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
11. do activities that are good for my child even in times of stress.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
12. feel that I can get the services and supports that my child and family need.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
13. understand how the Early Intervention system works.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
14. be able to evaluate how much progress my child is making.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
15. feel that my child will be accepted and welcomed in the community.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
16. feel that my family will be accepted and welcomed in the community.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
17. communicate more effectively with the people who work with my child and family.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
18. understand the roles of the people who work with my child and family.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
19. know about my child's and family's rights concerning Early Intervention services.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
20. do things with and for my child that are good for my child's development.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
21. understand my child's special needs.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
22. feel that my efforts are helping my child.	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
Other Information	
County of residence:	
Child's age when first referred to EI:	
Child's race/ethnicity:	<input type="radio"/> White <input type="radio"/> Black or African-American <input type="radio"/> Hispanic or Latino
	<input type="radio"/> Asian or Pacific Islander <input type="radio"/> American Indian or Alaskan Native
	<input type="radio"/> multiracial



Please return this form in the envelope provided to the Institute for Child Development.

Exit Form

Child Outcomes EXIT Summary Form

1. Date Completed: ____/____/____ **2. Child's Name:**

Mo Day Year First Last

3. Child's Date of Birth: ____/____/____ **4. Child's Sex:** M F **5. County/Borough/Residence:**
Mo Day Year (FIPS No.)

6. IFSP Team Members: Check all members who participated and completed this form. If individual forms are being completed by each participant, please check only the box for the participant completing *this* form:

Parent(s) Evaluator(s) EIO/D Service Coordinator Service Provider(s) Other: _____

7. Please rate the child's STATUS in each of the three functional areas, by circling the number which *BEST*

DESCRIBES THE CHILD'S CURRENT BEHAVIORS AND SKILLS:

7A. (1) To what extent does this child show **POSITIVE SOCIAL EMOTIONAL SKILLS (INCLUDING RELATIONSHIPS)** APPROPRIATE FOR HIS OR HER AGE and ACROSS A VARIETY OF SETTINGS AND SITUATIONS?

Completely	Somewhat	Emerging	Not Yet			
7	6	5	4	3	2	1

(2) Has the child shown any new skills or behaviors related to **POSITIVE SOCIAL EMOTIONAL SKILLS (INCLUDING RELATIONSHIPS)** since the ENTRY outcomes form was completed?

YES	1	If yes, briefly describe progress made, including new skills, behaviors, and/or functional abilities:
NO	2	

7B. (1) To what extent does this child **ACQUIRE AND USE KNOWLEDGE AND SKILLS** APPROPRIATE FOR HIS OR HER AGE and ACROSS A VARIETY OF SETTINGS AND SITUATIONS?

Completely	Somewhat	Emerging	Not Yet			
7	6	5	4	3	2	1

(2) Has the child shown any new skills or behaviors related to **ACQUIRING AND USING KNOWLEDGE AND SKILLS** since the ENTRY outcomes form was completed?

YES	1	If yes, briefly describe progress made, including new skills, behaviors, and/or functional abilities:
NO	2	

The EXIT CHILD OUTCOMES SUMMARY FORM IS COMPLETED FOR CHILDREN IN OUTCOME COHORTS WHO HAVE RECEIVED EARLY INTERVENTION SERVICES FOR AT LEAST SIX MONTHS. The form should be completed at the IFSP team meeting held closest to the date the child will EXIT the EIP.

Child Outcomes EXIT Summary Form

(Page 2)

7C. (1) To what extent does this child **TAKE APPROPRIATE ACTION TO MEET NEEDS** APPROPRIATE FOR HIS OR HER AGE and ACROSS A VARIETY OF SETTINGS AND SITUATIONS?

Completely	Somewhat	Emerging	Not Yet
7	6	5	4
		3	2
			1

(2) Has the child shown any new skills or behaviors related to **ACQUIRING AND USING KNOWLEDGE AND SKILLS** since the ENTRY outcomes form was completed?

YES	1	If yes, briefly describe progress made, including new skills, behaviors, and/or functional abilities:
NO	2	

8. Please check the appropriate boxes below to indicate the **TYPES OF SUPPORTING EVIDENCE** used by the IFSP Team to support these ratings, for **EACH OUTCOME AREA**:

Outcome	Type of Evidence (Check ALL that apply for each outcome)				
	Criterion-Referenced Test	Clinical Assessment	Evaluator(s) Observation	Parent/caregiver Observation	
Standardized Test					
Social Emotional Skills	☐	☐	☐	☐	☐
Acquiring/Using Knowledge/skills	☐	☐	☐	☐	☐
Taking Action to Meet Needs	☐	☐	☐	☐	☐

9. Please list the primary test(s) used as evidence for each outcome, if any.

Outcome	Test Number(s) from Instruction Sheet
Social Emotional Skills	Test No. __ Test No. __ Test No. __ Test No. __ Test No. __ Test No. __
Acquiring/Using knowledge/skills	Test No. __ Test No. __ Test No. __ Test No. __ Test No. __ Test No. __
Taking Action to Meet Needs	Test No. __ Test No. __ Test No. __ Test No. __ Test No. __ Test No. __

Outcome	Please write in the Name/edition of any <u>OTHER</u> test used <u>NOT LISTED ABOVE</u>
Social Emotional Skills	
Acquiring/Using knowledge/skills	
Taking Action to Meet Needs	

ATTACHMENT C: SUNY Buffalo ECO Data System Security Protocol



POPULATION HEALTH OBSERVATORY



"Dedicated to improving health through population based research."

SUNY BUFFALO ECO DATA SYSTEM SECURITY PROTOCOL

In Collaboration with:

Department of Biostatistics

NYS Department of Health, Bureau of Early Intervention

October 26, 2006

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1 Introduction

The Population Health Observatory of the School of Public Health and Health Professions at the State University of New York at Buffalo (henceforth referred to as the [PHO or SUNY Buffalo](#)) has recently entered into an agreement with the New York State Department of Health ([DOH](#)) Early Intervention Program ([EIP](#)) to develop a statewide data collection system. This system will respond to a Federal mandate that each state collect data on recently developed early childhood outcomes ([ECO](#)). The data collection system will be referred to herein as the ECO Data System, or ECODS.

In addition to reporting to the Federal Government, EIP personnel will use accumulated data for evidence-based management and evaluation of the EIP. In addition to developing and managing the ECO Data System, the [PHO](#) will conduct statistical analyses and, when requested, scientific studies to aid program staff in this work.

The purpose of this document is to present the policies and procedures to be followed by the PHO to ensure tight security of the ECO Data System and confidentiality of the ECO data. Any modifications to the system will require approval by [DOHEIP](#) and the DOH Chief Security Officer.

2 Physical and Environmental Security Policy

2.1 Physical Security Perimeter

Physical security of State Entity (SE) data in the SUNY Buffalo ECO Data System (ECODS) will be achieved by creating physical barriers around the assets being protected. Each barrier establishes a security perimeter that requires a method of access control to gain entry. Data collected by the ECO Data System will be protected by a three-tiered perimeter. The system servers and data storage device will be secured in a locked server cabinet, in an office locked when not in use, and in a building with access restricted only to authorized individuals during non-working hours.

2.2 Physical Security of Equipment

Computer equipment must be physically protected from security threats and environmental hazards. The Population Health Observatory ([PHO](#)) of the School of Public Health and Health Professions at the University at Buffalo will house the ECODS equipment in a locked server cabinet in a secure office to prevent security threats. The cabinet itself will provide a clean, dry environment and will contain the ECODS servers, storage devices, peripherals, and UPS equipment to protect against electrical surges and power failures.

2.3 Physical Security of Records

The physical security of records must be maintained in order to prevent unauthorized access. The following protocol for closing up at the end of each work day will be followed:

- lock all records, memoranda, and documents with confidential data in the storage cabinets;
- lock the door to the offices;

- issue keys only to individuals who have authorized access to the designated security zone.

2.4 Security Training

[DOH](#) staff will conduct security and confidentiality procedures training for [SUNY Buffalo](#) staff before initiating data collection and analysis. Subsequently, all data collection and analysis operations will be performed according to the processes outlined in the document “New York State Department of Health Division of Family Health New York State Early Intervention Program Procedures for Protecting Confidentiality of [ECO](#) Child and Family Survey Data,” which will serve as the basis for the confidentiality training.

2.5 Data Entry Procedures

Because the ECODS will not sit on any untrusted networks (as described in **Section 4**), data will arrive via paper and be incorporated into the ECODS in-house. [Child](#) or [Family](#) Survey Forms should be maintained in a secure location using the procedures specified to protect forms and computer records described under **Section 2.3**. Child or Family Survey Forms that have been edited will be prepared for data entry by batching them into units of 25 and by the completion of a batch cover sheet. The batch cover sheet will accompany the batched units at all times. The batched units will be logged out of and entered into the data entry log by PHO personnel. The internal data entry procedure will be as follows:

- batch forms into units of 25;
- complete the batch cover sheet;
- log the batched forms into the data entry log;
- hand-carry the batched forms to and from the data entry machine, and do not leave the forms unattended at the data entry machine;
- use the data entry instructions to create a unique batch file;
- record completion of the data entry in the log and notify the data-entry supervisor of all completed entries;
- follow procedures specified to protect forms and computer records.

3 Communications and Network Management Policy

3.1 Vulnerability Scanning

1. All ECODS hosts that will be directly or indirectly accessible from inside the SUNY Buffalo ECO Data System network will be scanned for vulnerabilities and weaknesses before being installed on the network, and after software, operating system, or configuration changes are made. PHO IT personnel will perform monthly scans of ECODS systems to ensure that no major vulnerabilities have been introduced into the environment.

2. PHO IT personnel will define and test a process for vulnerability scanning that will be followed by those authorized to perform the scanning. The process will rely heavily on the use of industry-standard scanning software (e.g. Nessus, www.nessus.org) with the following characteristics:
 - *Scalability*. Runs on variously powered servers and adapts to networks of increasing complexity.
 - *Smart Service Recognition*. Recognizes services running on non-standard ports.
 - *Multiple-Service Recognition*. Able to test hosts running the same service twice or more.
 - *SSL Support*. Able to test SSL-ized services such as https and imaps.
 - *Attack Mode*. Can simulate an intruder attack for “realistic” testing.
3. The ECODS System Administrator will review the output of scanning promptly, evaluate the risk of any vulnerability detected, and mitigate each vulnerability as appropriate. Following these actions, the System Administrator will provide a brief summary report of the vulnerability testing to [EIP](#).

3.2 Application Security Testing and Intrusion Detection

1. Because the ECODS will provide information across a network, the ECODS System Administrator will perform monthly application security tests to determine whether:
 - unauthorized individuals can make unauthorized changes to an application;
 - users can access an application and cause it to perform unauthorized tasks;
 - unauthorized individuals can access, destroy, or change any data; or
 - unauthorized individuals can access the application and cause it to take actions unintended by the application designers.
2. The ECODS System Administrator will install and maintain an industry-standard Intrusion Detection System (IDS; e.g. Snort, www.snort.org) with the following characteristics:
 - Capable of performing real-time traffic analysis and packet logging on IP networks.
 - Performs protocol analysis.
 - Performs content searching and matching.
 - Able to detect updatable “signatures” of various attacks and probes.
 - Able upon such detection to immediately alert the appropriate [PHO](#) IT personnel.
3. The ECODS System Administrator will review any IDS alerts promptly, evaluate the risk of any vulnerability detected, and mitigate each vulnerability as appropriate.
4. The ECODS System Administrator will update the tools used to perform intrusion detection as necessary to ensure that recently discovered vulnerabilities in other systems are included in testing.

3.3 External Connections

Because the Internet is inherently insecure, access to it will be prohibited from any device that is connected to any part of the [ECO](#) Data System network, unless specifically authorized by the ECO Data System Administrator as a necessary part of the ECODS.

4 Network Configuration Policy

We list below the characteristics of network configurations for the basic network types that comprise the ECO Data System, and present organizational requirements for dealing with outside networks such as the Internet.

4.1 All Networks

Characteristics common to all networks within the ECO Data System:

- eavesdrop-proof through the use of secure hubs or switches, or both;
- isolation from other networks by secured network devices such as firewall and stateful routers;
- logging of both successful and failed access attempts by all network perimeter devices;
- logs stored on protected hosts;
- logs reviewed by the System Administrator at least once every business day.

4.2 Untrusted Networks

An *untrusted network* is a network outside the direct control of the [SUNY Buffalo](#) ECO Data System Administrator, e.g. the Internet. Organizational requirements for dealing with untrusted networks follow:

- No devices in the SUNY Buffalo ECO Data System network will sit on an untrusted network.

4.3 Private Networks

A *private network* is an internal network that hosts internal-only applications and servers. For example, the ECODS reporting server will sit on a private network. The characteristics of private networks within the ECODS:

- devices will be protected by packet-filtering firewalls or firewall-grade routers;
- devices will be protected in a secure state;
- an automated virus-protection solution (e.g. Symantec AntiVirus) will be in operation;
- network logs will be archived for at least 6 months;

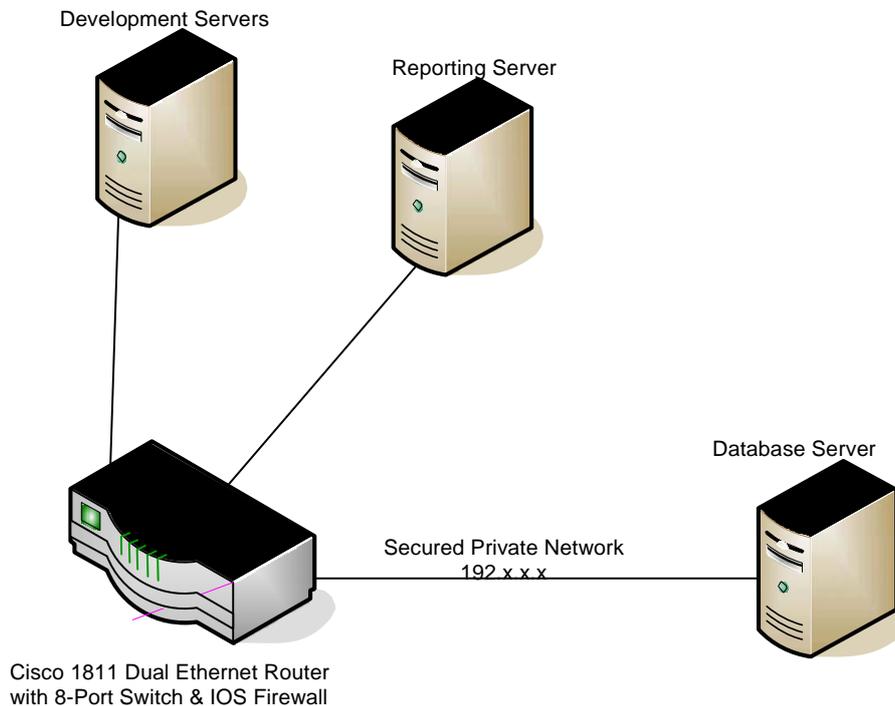
- application logging will be activated and frequently reviewed by the ECODS Administrator;
- access to systems will be limited to appropriate persons who have been approved by the data owners;
- no inbound connectivity from untrusted networks will be permitted;
- inbound connectivity from e-commerce networks will be permitted provided that the private network devices run robust operating systems that are hardened against attack (*hardening* includes loading of all applicable patches as they are released and removing unneeded services), and that access will be limited to only the scope of need;
- outbound connectivity will be limited to needed services;
- within-network connectivity through wireless communications will be prohibited;
- access to confidential or sensitive information will be allowed only through SQL Server's mixed (Windows NT and SQL Server) authentication mode.

4.4 Secured Private Networks

A *secured private network* hosts servers that hold an organization's most sensitive information and that are secured from other types of networks; e.g., a network with database servers containing patient-identifying data. For example, the database server of the ECODS will be part of a secured private network. Some characteristics of secured private networks on the ECODS follow:

- no user machines will sit on a secured private network;
- devices will be protected by packet-filtering firewalls or firewall-grade routers;
- devices will run robust operating systems that are hardened against attack (*hardening* includes loading of all applicable patches as they are released and removing unneeded services);
- network logs will be archived for at least 6 months;
- application logging will be activated and reviewed at least once every business day;
- confidential or sensitive information stored on devices in this network will be secured independently from network access security control (e.g. separate password files);
- access to systems is limited to appropriate persons who have been approved by the data owners;
- inbound and outbound connectivity is limited to needed services;
- no inbound connectivity from untrusted networks will be permitted;
- authentication systems will be centrally managed;
- sensitive data will be secured through the new data encryption capabilities of SQL Server 2005.

4.5 SUNY Buffalo ECO Data System Network Configuration Policy Diagram



5 Operational Management Policy

5.1 Separation of Development, Test, and Production Environments

1. During the development of the [ECO](#) Data System, we will maintain physical or logical separation of the development, test, and production environments. We will implement the following controls:
 - development software and tools will be maintained on computer systems isolated from the production environment—this isolation will be provided by physically separate machines or separate virtual-machine environments (e.g. as provided by VMware);
 - access to compilers, editors, and other system utilities (which would have been granted only to the ECODS System Administrator and authorized ECODS developers) will be removed from production systems when not required;
 - development and test machines will sit on a private network different from the secured private network on which the production data will be stored;
 - production data will not be used for development or testing;
 - logon procedures and environmental identification will be sufficiently unique for production testing and development.

2. Separation will be implemented between development and test functions. The SUNY Buffalo ECODS developers will use a stable quality assurance environment where user acceptance testing can be conducted and changes cannot be made to the program being tested.

5.2 System Planning and Acceptance

1. Because system and data availability is a security concern, advance planning and preparation will be performed to ensure the availability of adequate capacity and resources.
2. Storage and memory capacity demands will be monitored and future capacity requirements projected to ensure that adequate processing and storage capability is available when needed. This information will be used to identify and avoid potential bottlenecks that might present a threat to system security or user services.

5.3 Systems Change Control

1. The ECODS System Administrator will use a Systems Change Control Worksheet to plan and track scheduled systems changes (i.e. upgrades, patches, configuration updates, etc.) The Worksheet will be filled out as follows:
 - Provide a change request id (name or number).
 - Describe the change in the space provided.
 - Specify the change “goal” (upgrade, fix, maintenance, improvement, other).
 - Describe the systems and locations involved.
 - Specify the change priority and risk (high, medium, or low).
 - Specify an outage window, target install date, and estimated costs.
 - Select all relevant tasks and track status throughout the change process (pending, in progress, and completed).
2. Completed Systems Change Control Worksheets will be sent to [NYSDOH](#) for approval, without which approval system changes cannot be made. NYSDOH may reject certain system changes or independently require others not first proposed by the ECODS System Administrator.

5.4 Protection against Malicious Code

We will implement software and associated controls across the [SUNY Buffalo](#) ECO Data System to prevent and detect the introduction of malicious code. The introduction of malicious code such as a computer virus, network worm program, or Trojan horse could cause serious damage to the Data System. The ECODS System Administrator will implement controls to detect computer viruses and prevent them from being introduced into the Data System environment. On host systems or servers, the signature files will be updated daily or when the virus software vendor’s signature files are updated and published. (For example, at this writing, SUNY Buffalo holds a site license for Symantec AntiVirus, which will be installed on all ECODS computers.) All new operating system

and software patches will be tested by first installing them on the test or development systems before moving or installing them on the production systems; production systems will not receive software or operating system upgrades automatically.

5.5 Software Maintenance

1. All system software will be maintained at a vendor-supported level to ensure software accuracy and integrity.
2. Maintenance of SUNY Buffalo–developed software will be logged to ensure that changes are authorized, tested, and accepted by the [ECO](#) Data System management.
3. All known security patches will be reviewed, evaluated, and appropriately applied in a timely manner to reduce the risk of security incidents that could affect the confidentiality, integrity, and availability of SE data or software integrity.

5.6 Information Back-Up

To ensure that interruptions to normal ECO Data System operations are minimized, the critical ECO Data System applications and processes will be protected from the effects of major failures, through plans that meet the IT backup and recovery requirements of the SE. Back-ups of critical data and software will be performed regularly. Among other things:

- a unshared SAN disk array on the secured private network will provide space for application and database backups;
- DVDs and external hard drives used for backup storage which is physically separate from the server cabinet will be kept in an on-site fire safe;
- a robust software package like ARCserve will perform the backup transfers;
- extra hot-swappable hard drives will be kept to replace failed hard drives in the servers or SAN, and those extra drives will be tested every 6 months to ensure their integrity.

5.7 System Security Checking

1. The ECO Data System Administrator will conduct technical security reviews of systems and services that process or store sensitive or confidential information or provide support for critical processes to ensure compliance with implementation standards and for vulnerabilities to subsequently discovered threats. Reviews of systems and services that are essential to supporting a critical ECO Data System function will be conducted at least once every year. Reviews of a representative sample of all other systems and services will be conducted at least once every 24 months.
2. Any deviations from expected or required results that are detected by the technical security review process will be recorded and corrected immediately. In addition, the ECO Data System Administrator will initiate investigation of the deviations (including the review of

system activity log records if necessary) and send a summary report to EIP. Areas found deficient will be re-evaluated in 6 months.

3. [DOH and EIP](#) may provide further review with not less than 7 days' notice.

6 Access Control Policy

1. To preserve the properties of integrity, confidentiality, and availability, [SUNY Buffalo's ECO Data System](#) information assets will be protected by logical and physical access control mechanisms commensurate with the value, sensitivity, consequences of loss or compromise, legal requirements, and ease of recovery of these assets.
2. The DOH Early Intervention Program Director or an official DOH designee will determine who should have access to protected resources within the Program's jurisdiction, and what those access privileges will be (read, update, etc.). These access privileges will be granted in accordance with the user's job responsibilities.
3. The [ECO Data System Administrator](#) will set and review logging of all System access as described in **Section 4**.

6.1 PHO Data Classification Policy

1. Responsibility for Data Management

Data is a critical asset of the [SUNY Buffalo's Population Health Observatory \(PHO\)](#). All members of the PHO have a responsibility to protect the confidentiality, integrity, and availability of data generated, accessed, modified, transmitted, stored, or used by the PHO, irrespective of the medium on which the data resides and regardless of format (such as in electronic, paper, or other physical form).

PHO personnel are responsible for implementing appropriate managerial, operational, physical, and technical controls for access to, use of, transmission of, and disposal of PHO data in compliance with this policy.

Data owned, used, created, or maintained by the PHO is classified into the following three categories:

- Public
- Official Use Only
- Confidential

PHO personnel should carefully evaluate the appropriate data classification category for their information.

2. Data Classifications

- (a) *Public Data.* Public data is information that may or must be open to the general public. It is defined as information with no existing local, national, or international legal restrictions on access or usage. Public data, while subject to University disclosure rules, is available to all members of the University community and to all individuals and entities external to the University community.

By way of illustration only, some examples of Public data include:

- publicly posted press releases
- publicly posted schedules of events

- (b) *Official Use Only Data.* Official Use Only data is information that must be guarded due to proprietary, ethical, or privacy considerations, and must be protected from unauthorized access, modification, transmission, storage, or other use. This classification applies even though there may not be a civil statute requiring this protection. Official Use Only data is information that is restricted to members of the PHO who have a legitimate purpose for accessing such data.

By way of illustration only, some examples of Official Use Only data include:

- employment data
- PHO partner or sponsor information where no more restrictive confidentiality agreement exists
- internal telephone books and directories

Official Use Only data:

- must be protected to prevent loss, theft, unauthorized access and/or unauthorized disclosure;
- must be stored in a closed container (e.g. file cabinet, closed office, or special area where physical controls are in place to prevent disclosure) when not in use;
- must not be posted on any public website;
- must be destroyed when no longer needed subject to the University Record Retention Policy. Destruction may be accomplished by:
 - “hard copy” materials must be destroyed by shredding or another process that destroys the data beyond either recognition or reconstruction. After destruction, materials may be disposed of with normal waste;
 - electronic storage media shall be sanitized appropriately by overwriting or degaussing prior to disposal. Disposal of electronic equipment must be performed in accordance with the University’s Electronic Equipment Recycling Policy.

- (c) *Confidential Data.* Confidential data is information protected by statutes, regulations, University policies, or contractual language. Managers may also designate data as Confidential.

Confidential data may be disclosed to individuals on a need-to-know basis only.

Disclosure to parties outside the University should be authorized by executive management.

By way of illustration only, some examples of Confidential data include:

- medical records
- Social Security Numbers
- personnel and/or payroll or records
- any data identified by government regulation to be treated as confidential, or sealed by order of a court of competent jurisdiction.

Confidential data:

- when stored in an electronic format, must be protected with strong passwords and stored on servers that have protection and encryption measures to protect against loss, theft, unauthorized access, and unauthorized disclosure;
- must not be disclosed to parties without explicit management authorization;
- must be stored only in a locked drawer or room or an area where access is controlled by a guard, lock, and/or card reader, or that otherwise has sufficient physical access control measures to afford adequate protection and prevent unauthorized access by members of the public, visitors, or other persons without a “need to know”;
- when sent via fax must be sent only to a previously established and used address or one that has been verified as using a secured location;
- must not be posted on any public website;
- must be destroyed when no longer needed subject to the University Record Retention Policy. Destruction may be accomplished by:
 - “hard copy” materials must be destroyed by shredding or another process that destroys the data beyond either recognition or reconstruction. After destruction, materials may be disposed of with normal waste;
 - electronic storage media shall be sanitized appropriately by degaussing prior to disposal. Disposal of electronic equipment must be performed in accordance with the University’s Electronic Equipment Recycling Policy.

Regarding DOH data, the Office of the Chief Information Security Officer must be notified in a timely manner if data classified as Confidential is lost, disclosed to unauthorized parties or suspected of being lost or disclosed to unauthorized parties, or if any unauthorized use of the ECODS information systems has taken place or is suspected of taking place.

3. Enforcement

Enforcement measures implemented for data security will be dictated by the data-classification level. Measures will include an appropriate combination of the following:

- encryption requirements
- data protection and access control
- documented backup and recovery procedures
- change control and process review
- data-retention requirements

- data disposal
- audit controls
- storage locations
- user awareness

6.2 User Registration and Management

1. A user management process will be established and documented by the [SUNY Buffalo](#) ECO Data System management to outline and identify all functions of user management, to include the generation, distribution, modification, and deletion of user accounts for access to resources. The purpose of this process is to ensure that only authorized individuals have access to [ECO](#) Data System applications and information and that these users only have access to the resources required for authorized purposes.
2. The user management process will include the following sub-processes that assign, monitor, and review user authentication:
 - enrolling new users;
 - removing user IDs;
 - granting “privileged accounts” to a user;
 - removing “privileged accounts” from a user;
 - periodically reviewing “privileged accounts” of users;
 - periodically reviewing of users enrolled into the ECO Data System; and
 - assigning a new authentication token (e.g. password reset processing).
3. The appropriate information owner or other authorized officer will make requests for the registration and granting of access rights for State employees and individuals not employed by a SE.

6.3 Enrolling New Users

- Requests for new user accounts will be made in writing to the SUNY Buffalo ECO Data System management; each request should specify the access level desired for its corresponding account, and should include the usual: name, address, contact person, and e-mail, as well as other relevant information. Upon the acceptance of a request, the ECO Data System Administrator will create an account based on the specifications supplied by the ECODS management.
- SUNY Buffalo will create user accounts from this client data and assign usernames and initial passwords. This information will be stored encrypted in the ECODS database and used for all future Web-application authorizations. At this stage, all the user accounts will be merely *initialized*, but as yet unused.

- [SUNY Buffalo](#) will provide username information to new users through e-mail. Users either will receive a paper letter containing an initial password and instructions on logging in and how to change the password, or will receive an initial password and instructions from a face-to-face meeting with the ECODS Administrator.
- All new users will undergo confidentiality training as described in **Section 2.4**.
- SUNY Buffalo will create a user-management utility to handle user accounts, so e.g. turning off an account or modifying its privileges is a simple matter. Access to this utility will be role-based and users will be assigned roles within the limits of their job requirements. Developers will not be authorized to manage production accounts.
- The following “ECODS roles,” whose definitions are currently being refined by SUNY Buffalo [PHO](#) and [EIP](#) personnel, are planned to govern which SQL Server roles are given to the ASP.NET application used to get access to ECODS data.
 - *Data Entry*. Users with this role will only be able to add records to the family and child survey data as forms are received. Currently only one PHO employee, Amy Prescott, will have Data Entry permissions.
 - *Quality Control*. Users with this role will be able to write to, delete from, and read the family and child tables as necessary to perform quality control activities. Currently only one PHO employee, Amy Prescott, will have Quality Control permissions.
 - *Project Coordinator*. Users with this role will be able to write to, delete from, and read the family and child tables, and also to read other tables as needed, including de-identified KIDS system data, to fulfill the terms of the MOU and to perform quality control activities. Currently only one PHO employee, Amy Prescott, will have Project Coordinator permissions.
 - *Data Analysis*. Users with this role will be able only to read de-identified family and child tables summaries or de-identified KIDS tables for the purpose of statistical analysis and data reporting.
 - *System Administrator*. Users with this role will have full data-manipulation permissions. Currently only two PHO employees, Li Yan, the ECODS System Administrator, and Dr. Randy Carter, the Project Director, will have System Administrator permissions. The Project Director will be granted System Administrator permissions for the purpose of providing backup to the ECODS System Administrator and to assure continuity in the event of employee turnover.
- *N.B.* During this current initial phase of [ECO](#) Data System development, only the ECODS System Administrator will have full access to production data, and all requests by authorized users for appropriately de-identified data will be handled by the System Administrator. Development and Quality Assurance will be done with faked or simulated data not attached to any real persons. Before the ECODS project enters its Web phase, user roles and management will have been better defined through requirements discussions with [EIP](#) personnel, and this document will be augmented then to consider the finer granularity.

6.4 First-Time Logons by Users

- The user will receive from [SUNY Buffalo](#) an e-mail with a username, and also a letter with a password, which together will allow logon to the ECO Data System for the first time. A first-time session will start by announcing the requirements that the user change the password and verify all of the information we have, especially the e-mail address. The user will also provide answers to 7 “secret questions.” The answer to the questions will be stored in the ECO Data System database, and used as a challenge in case of a lost password in the future. Some possible secret questions are:
 - What is the first and last name of your first boyfriend or girlfriend?
 - Which phone number do you remember most from your childhood?
 - What was your favorite place to visit as a child?
 - Who is your favorite actor, musician, or artist?
 - What was your favorite teacher’s name?
 - Who is your favorite fictional character?
 - What is the last name of your best friend plus the last 4 digits of your telephone number?

(The final set of questions will be approved by the NYSDOH ISO.)

If the user has properly followed the first-time logon instructions above, the ECO Data System will now put the account on *pending* status. Concurrently, the System will send a notification to the System Administrator by e-mail to ask for verification and activation of the account. The System will display a page informing the user that the account will be activated after the application is reviewed by the System Administrator, and will also send an e-mail to the user. These actions will all be recorded in the database.

- The System Administrator, if satisfied the user’s credentials, will use the user-management utility to activate the user account. The system will change the account to *active* status, and the user can start to input data.

6.5 Logon Banner

Logon banners will be implemented on all systems where that feature exists to inform all users that the system is for ECO Data System business or other approved use consistent with ECO Data System policies, and that user activities may be monitored. Logon banners will be presented during the authentication process before the authentication itself.

6.6 User Authentication Process

User authentication will occur at many different points during an ECODS application session, in the following sequence:

- Users will logon to an ASP.NET application through a Web browser.

- This simple authentication will provide the ASP.NET application with appropriate SQL Server login/user authentication to connect to allowed databases. SQL Server roles will be provided to the application based on “ECODS roles” that will have been defined before the Web phase of the ECODS project. (N.B. Until these “ECODS roles” are better defined, only the ECODS System Administrator will have full access to production data, and all re-quests by authorized users for appropriately de-identified data will be handled by the System Administrator.)
- Users will then have, insofar as they’re allowed, access to the data (possibly delivered in XML) or summary reports (possibly delivered in XML or PDF).
- The ECODS System will handle the process of user access with validation by DOH and will be monitored and audited carefully, as described elsewhere in this document.

6.7 Lost Password

- The user will follow a link on the authorization page to request help for a lost password. Application for a new password involves entering all relevant user information (name, job title, address, e-mail, business phone number, and supervisor name), and also the challenge information (4 of the 7 questions must be answered correctly) given at the first logon. If this fails, the user will have to contact the System Administrator directly to ask for a temporary password, then await the System Administrator’s response as in the third step below. If a face-to-face meeting (with identification of the user by picture ID or supervisor if necessary) of the user and System Administrator to resolve the lost-password problem is impossible, then the user may have to be re-enrolled into an account starting from scratch, as described in **Section 6.3**.
- If the information is validated, the system will change the account to *pending* and send e-mail to the System Administrator. A description of this action will be displayed and e-mailed to the user, who will need to wait to be contacted by the System Administrator.
- If the System Administrator decides that the request (either from recorded information or direct contact as described in the first step above) is legitimate, then the user-management utility can be used to reset the user account (to status *change password*) and to generate a temporary password. The System Administrator will decide on a proper way to transfer the temporary password to the user. Acceptable transfer might occur via USPS mail or a direct meeting with the user.
- The user logs in using the temporary password, and is prompted to change it to a new password, after which the account becomes *active* again. Whenever the user needs to change a password, either voluntarily or by our request, the action will be recorded in the database, and a notification will be sent to the System Administrator and to the contact person’s e-mail account as a reminder and verification.
- If a temporary password request cannot be honored because of insufficient challenge responses or suspicion of deceit, the System Administrator will get relevant personal information from the user (name, job title, address, e-mail, business phone number, and supervisor

name) and then ask the [SUNY Buffalo](#) ECO Data System management for a review of the request.

6.8 User Password Management

1. Password standards will be developed and implemented to ensure that all authorized individuals accessing [ECO](#) Data System resources follow proven password management practices. These password rules will be mandated by automated system controls whenever possible. Passwords must:
 - not be stored in clear text;
 - not be the same as the username;
 - not be easily guessed or subject to disclosure through a dictionary attack;
 - be kept confidential;
 - be changed at regular intervals of three months;
 - be changed at first logon from temporarily assigned passwords;
 - be at least 8 characters long and contain a mix of alphabetic, numeric, or special characters; and
 - not be included in any automated logon process, e.g. stored in a macro or function key, in a Web browser, or in application code;
 - be stored encrypted in the database as part of a “password history” that includes a user’s twelve most recent passwords.
2. To ensure good password management, password standards will be implemented on all ECO Data System platforms.

6.9 Accounts Management

The issuance and use of accounts will be restricted and controlled as described in **Section 6**. The system administrators will monitor account usage through system logs and database logs, and will promptly investigate any suspected misuse while concurrently informing the SUNY Buffalo ECO Data System management of the suspected misuse. Potential or suspected breaches of confidentiality will be handled according to procedures outlined in the “Protecting Confidentiality of ECO Child and Family Survey Data” document.

6.10 Application Access Control

Access to ECO Data System applications will be restricted to those individuals who have a need to access those applications in the performance of their job responsibilities. Access to source code for applications will be restricted to the system administrator and one or two other “super users” designated by the Director of the Population Health Observatory at SUNY Buffalo.

7 Security Checklists

7.1 Planning Phase

SUNY Buffalo will use this checklist to track progress in planning the security of the ECO Data System.

ECODS Security Planning Checklist		Planning completed?
Physical and Environmental Security		
1.	Physical Security Perimeter	X <input type="checkbox"/>
2.	Physical Security of Equipment	X <input type="checkbox"/>
3.	Physical Security of Records	X <input type="checkbox"/>
4.	Security Training	X <input type="checkbox"/>
5.	Data Entry Procedures	X <input type="checkbox"/>
Communications and Network Management		
1.	Vulnerability Scanning	X <input type="checkbox"/>
2.	Application Security Testing and Intrusion Detection	X <input type="checkbox"/>
Operational Management Policy		
1.	Separation of Development, Test, and Production Environments	X <input type="checkbox"/>
2.	System Planning and Acceptance	X <input type="checkbox"/>
3.	Systems Change Control	X <input type="checkbox"/>
4.	Protection against Malicious Code	X <input type="checkbox"/>
5.	Software Maintenance	X <input type="checkbox"/>
6.	Information Back-Up	X <input type="checkbox"/>
7.	System Security Checking	X <input type="checkbox"/>
Access Control Policy		<input type="checkbox"/>
1.	PHO Data Classification Policy	X <input type="checkbox"/>
2.	User Registration and Management	X <input type="checkbox"/>
3.	Enrolling New Users	X <input type="checkbox"/>
4.	First-Time Logons by Users	X <input type="checkbox"/>
5.	Logon Banner	X <input type="checkbox"/>
6.	User Authentication Process	X <input type="checkbox"/>
7.	Lost Password	X <input type="checkbox"/>
8.	User Password Management	X
9.	Accounts Management	X
10.	Application Access Control	X

Signature of Project Manager: _____

7.2 Implementation Phase

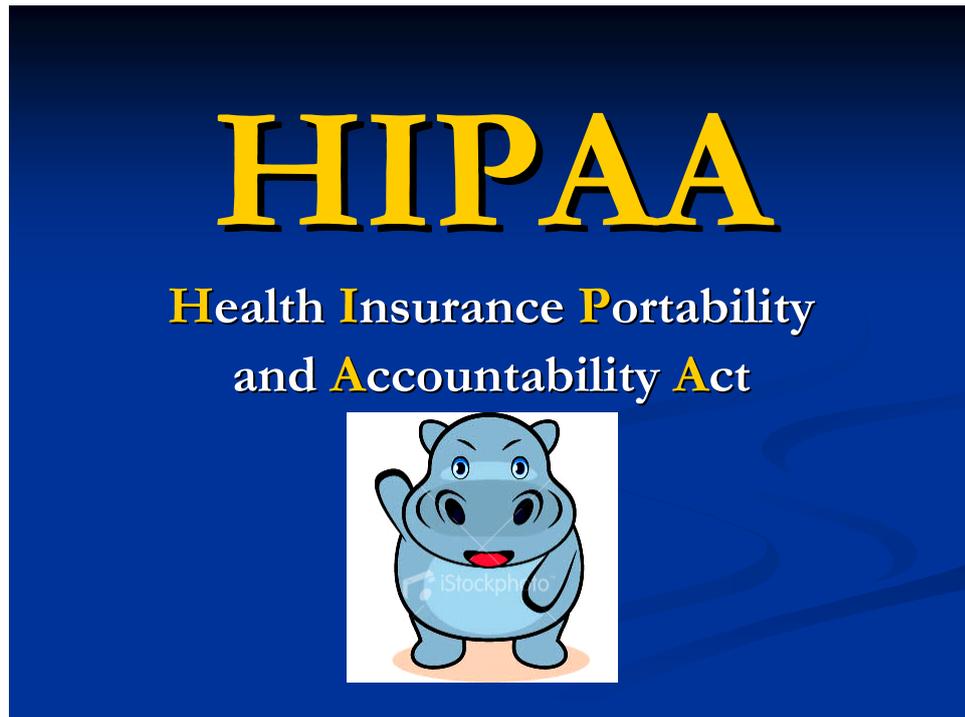
[SUNY Buffalo](#) will use this checklist to track progress in implementing the security of the ECO Data System. It will be augmented by more detailed subcategories as the processes clarify them- selves in practice.

ECODS Security Implementation Checklist		
Physical and Environmental Security		Implemented?
1.	Physical Security Perimeter	<input type="checkbox"/>
2.	Physical Security of Equipment	<input type="checkbox"/>
3.	Physical Security of Records	<input type="checkbox"/>
4.	Security Training	<input type="checkbox"/>
5.	Data Entry Procedures	<input type="checkbox"/>
Communications and Network Management		
1.	Vulnerability Scanning	<input type="checkbox"/>
2.	Application Security Testing and Intrusion Detection	<input type="checkbox"/>
Operational Management Policy		
1.	Separation of Development, Test, and Production Environments	<input type="checkbox"/>
2.	System Planning and Acceptance	<input type="checkbox"/>
3.	Systems Change Control	<input type="checkbox"/>
4.	Protection against Malicious Code	<input type="checkbox"/>
5.	Software Maintenance	<input type="checkbox"/>
6.	Information Back-Up	<input type="checkbox"/>
7.	System Security Checking	<input type="checkbox"/>
Access Control Policy		
1.	PHO Data Classification Policy	<input type="checkbox"/>
2.	User Registration and Management	<input type="checkbox"/>
3.	Enrolling New Users	<input type="checkbox"/>
4.	First-Time Logons by Users	<input type="checkbox"/>
5.	Logon Banner	<input type="checkbox"/>
6.	User Authentication Process	<input type="checkbox"/>
7.	Lost Password	<input type="checkbox"/>
8.	User Password Management	<input type="checkbox"/>
9.	Accounts Management	<input type="checkbox"/>
10.	Application Access Control	<input type="checkbox"/>

Signature of Project Manager: _____

ATTACHMENT D: PHO HIPAA Training Slides

Double click below to view the UB-PHO HIPAA Training Presentation.



ATTACHMENT E: NYS-DOH Security and Confidentiality Training Slides

Double click below to view the NYS-DOH Security and Confidentiality Training Presentation.



ATTACHMENT F: Employee Confidentiality Agreement Form

Attachment 1 NEW YORK STATE DEPARTMENT OF HEALTH

EMPLOYEE ATTESTATION OF CONFIDENTIALITY

FOR STAFF WHO WORK WITH HIGHLY CONFIDENTIAL DATA

As an employee of the Research Foundation (SUNY Buffalo/SUNY Binghamton, I understand that I may have access to confidential information on persons or clients of sites involved in our work. This information includes, but is not limited to electronic or paper records or information given orally during an interview or through other related contact. Information may also come from records. Examples of such information include names, addresses, telephone numbers, medical conditions, living arrangements, social history, etc.

I hereby acknowledge that I have received a copy of New York State Department of Health Procedures for Protecting Confidentiality ECO Child and Family Survey Data and I will abide by all appropriate laws, regulations and protocols regarding the confidentiality of protected information. I understand that any infraction of these rules will be documented and that violation of these standards is subject to appropriate disciplinary action(s) on the part of my employer, which could include being discharged from my position and/or being subject to other penalties. I understand that violations will be pursued as allowed by the laws of New York State. By initialing the following statements and signing this attestation, I agree that:

INITIAL BELOW:

- _____ I will not discuss any identifying information except in the performance of job-related duties.
- _____ I will conduct telephone conversations and/or conference calls that require the discussion of identifiers as discreetly as possible and only within the restricted access area out of hearing range of unauthorized staff.
- _____ I will handle highly confidential data as discreetly as possible and I will keep any highly confidential files that I am working with out of the view of unauthorized persons.
- _____ I will not receive visitors who are not authorized in the restricted access area that I work in unless all highly confidential materials are properly secured.
- _____ All highly confidential files, including portable media, will be kept in a double-locked file cabinet when not in use.
- _____ When working with highly confidential files on my computer, I will log off when I am finished to prevent unauthorized access to confidential files and databases, and I will log off and power down my computer at the end of each day.
- _____ Electronic files containing highly confidential data will be zipped, encrypted, password protected and stored in the appropriate place on the LAN.
- _____ My computer will be protected by power on (boot up) and screen saver passwords I will not disclose these or any passwords to unauthorized persons. I will not share my authentication token with anyone.
- _____ I will not allow software to retain my password on file (auto connect).

(continued on next page)

_____ I am responsible for preventing unauthorized access to or use of my keys, passwords, authentication token and alarm codes.

_____ I will not copy, write, download, or store any highly confidential data to any hard drive or portable media (including but not limited to floppy, cd, zip disk or flash drive) that can be removed from the restricted access area without assuring that the data are encrypted.

_____ I will not access highly confidential information through dial-in or VPN from a remote computer.

_____ I will not fax any highly confidential data.

_____ I will not e-mail any highly confidential data to any e-mail address, including personal e-mail accounts.

_____ Any data transfer will be done via the secure file transfer utility on the HIN (DOH or county) or SDN (CDC) using the appropriate encryption and only to authorized persons or through encrypted files that are mailed via the U.S. Postal Service Registered Mail.

_____ I will ensure that any information carried in the field does not contain linked data.

_____ When transporting information that is highly confidential I will employ appropriate security measures to ensure that the material remains protected.

_____ Any paper document to be disposed of that contains highly confidential information will be crosscut shredded in a restricted access area. Electronic documents must be deleted using the Purge utility.

_____ Reports, records or information may be released only in accordance with established policies.

_____ Any exception to these policies must have written pre-approval of the Director, Policy and Planning, or his/her designee.

_____ I understand and agree that I am bound by these policies, even upon resignation, termination or completion of my activities.



Employee Name (Please Print)

Employee Signature Date

Bureau/Division/Regional Off/County or Firm

Building and Room No./ City



I hereby certify that I have provided training for this employee on confidentiality and have provided a copy of pertinent New York State laws, regulations and policies regarding confidentiality.

Trainer Signature

Date

ATTACHMENT G: PHO Dataset Documentation Form

**POPULATION HEALTH OBSERVATORY
DATA SET DOCUMENTATION FORM**

TITLE OF DATA SET:

DATE:

LATEST UPDATE TO THIS FORM:

PROGRAMMER:

SOURCE AGENCIES:

SOURCE PERSON(S):

SOURCE DATA SETS:

NETWORK LOCATION OF SOURCE DATA:

OFF LINE LOCATION OF SOURCE DATA:

CONTENTS OF CURRENT DATA SET:

NETWORK LOCATION OF CURRENT DATA SET:

LOCATION OF ARCHIVED CURRENT DATA SET:

DATE ARCHIVED:

DOCUMENTATION: