

## Early Childhood Data Systems Workgroup Demonstration Project

Do Connecticut children in regulated early care and education settings fare better than those placed in unregulated early care and education settings? This policy question was the focus of a demonstration project involving the Office of Policy and Management’s Early Childhood Planning Office, the Governor’s Early Childhood Education Cabinet, and the Center for Public Health and Health Policy (CPHHP) at the UCONN Health Center that took place from fall 2012 to spring 2013. The goals of the demonstration project were to (a) demonstrate the value of integrating data across agencies to answer critical policy questions relevant to early childhood development and well-being, (b) test the feasibility of using the federated architecture developed for the Connecticut Health Information Network (CHIN) platform to link early childhood data collected and maintained by five different agencies, and (c) identify challenges in deploying a CHIN type platform to support a statewide Early Childhood Information System.

The target population for the demonstration project included children from the 2003 and 2004 Connecticut birth cohorts who participated in Connecticut’s childcare subsidy program, Care 4 Kids, prior to Kindergarten entry. Data from DPH, DCF, DDS, and DSS were needed to provide a comprehensive understanding of services received and child outcomes.

### Project Timeline

Discussion of a demonstration project was initiated in August 2012 meetings involving Myra Jones-Taylor, Director of Connecticut’s Early Childhood Planning Office, and Dr. Robert Aseltine, UCONN Professor and Deputy Director of CPHHP. A preliminary draft of the goals of the demonstration project established by the Data Systems Workgroup was forwarded to CPHHP on October 5<sup>th</sup> 2012. CPHHP researchers began reviewing the relevant scientific literature, identifying potential data sources in the state, and developing a project timeline. In addition to Dr. Aseltine’s time, CPHHP contributed the time of a Planning Specialist, Erin Havens, MPA, MPH, and assigned the project as the core task for a second-year UCONN Master’s in Public Administration student, Eric Horan, JD, who was hired for the academic year. The CPHHP team, Connecticut’s Early Childhood Planning Director, the ECEC Planning Director and key early childhood staff met during two planning meetings in November, agreeing on an aggressive timeline for the project, with an end date of February 2013. Table 1 illustrates the project milestones set to produce a final report by the February 2013 project end date.

**Table 1. Demonstration Project Timeline**

Deadline	Milestone
11/2012	Data dictionaries acquired
11/2012	Data elements defined and IRB/MOUs submitted to state agencies as needed
12/2012	IRB approved/MOU executed
1/2013	State agency data delivered to CPHHP
1/2013	CPHHP conducts data matching and analysis
2/2013	Draft report submitted to ECEC Data Systems Workgroup

Securing the data dictionaries and formalizing agency support at the Commissioner-level were set as immediate priorities. Acquisition of the data dictionaries was needed to define the data elements that would be requested from state agencies. Once obtained, the data elements of interest would be defined in Memoranda of Understanding and Institutional Review Board or other agency review applications between CPHHP and the state agencies. The team successfully collaborated on the following communications during the month:

- A letter to agency commissioners introducing the ECIS concept, the demonstration project, the need for data dictionaries, and the establishment of MOUs;
- An introductory email sent by the ECEC Planning Director to data workgroup representatives regarding the need to obtain data dictionaries;
- Follow-up emails and phone calls from CPHHP to Data Workgroup representatives about obtaining data dictionaries.

## Data Dictionary Request

Requests for data dictionaries were made to Data Workgroup members in mid-to-late November. CPHHP did not receive all the data dictionaries necessary for the project until the end of January (Table 2).

**Table 2. Response Time for Data Dictionary Requests**

Response Time	Entity	Data Source	Received
<1 day	SDE	PSIS, ED 166, Early Childhood Outcomes, SEDAC, TCS	11/15/2012
15 days	DPH	MAVEN	12/11/2012
22 days	SDE	PKIS , KIN-INV	12/6/2012; 1/3/2013
55 days	DCF	LINK	1/14/2013
56 days	DDS	Birth to Three	1/15/2013
65 days	DSS	Care4Kids	1/26/2013

State agency response times for sending the dictionaries ranged from the same day to 65 days, with three agencies taking 55 or more days. The lack of data dictionaries and, therefore, defined data elements led to a significant delay in CPHHP submitting the IRB applications and draft MOUs to state agencies. IRB and MOUs did not reach most state agencies for review until mid-to-late January, significantly later than the target date of November 2012.

## Noteworthy

It was not until the Data Systems Workgroup meeting held in December that the Workgroup reached a consensus that proceeding with the data demonstration project would be a beneficial step in working towards the development of an ECIS. In December, the Workgroup committed to the action item of acquiring and providing CPHHP with the data. In the prior month, the action item involved determining whether the Workgroup's focus should be the demonstration project or securing cross agency data sharing agreements for the larger system.<sup>1</sup> The internal debate within the Workgroup may in part explain some of the delay in providing data dictionaries.

<sup>1</sup>Project Director Report. CT Early Childhood Education Cabinet. November 15, 2012. Accessed 4/11/2013 from: <http://www.ctearlychildhood.org/project-director.html>

### Institutional Review Board/Human Investigation Committee and MOUs

As of 4/15/2013, the project had not been approved by agency review boards nor had Memoranda of Understanding been executed between the agencies and the UCONN Health Center (Table 3). All IRB applications were submitted by the end of January and draft MOUs were sent to SDE and DDS in January and DSS in February.

**Table 3. Memoranda of Understanding Execution Between Agencies and UCHC**

Response Time	Entity	Request	Status
7 days	SDE	MOU UCHC & SDE initial feedback	Received
20+ days	UCHC contracts	MOU UCHC & DDS	Not completed
33+ days	DDS	IRB	Not completed
33+ days	DPH	HIC	On hold <i>Commissioner is holding all "CHIN"-related IRBs</i>
46+ days	DSS	MOU UCHC & DSS Initial feedback	Not completed
47+ days	DCF	IRB	On hold <i>IRB is waiting to hear from administrator whether to rule on IRB. An administrator considers project "not research."</i>
60 days	DDS	MOU UCHC & DDS Initial feedback	Received
63+ days	UCHC contracts	MOU UCHC & SDE (initial draft for DDS, DSS)	Not completed

+ indicates approval has not occurred by April 15

The DPH HIC application was placed on hold while CHIN projects were considered in the context of "other data initiatives in the state."<sup>2</sup> The DCF application has been received and read by the IRB members but as of 4/5/2013 the IRB was awaiting further instruction from an administrator on whether to finish the review or withdraw the proposal. The administrator noted, the "project is not research and should not be treated as research."<sup>3</sup>

Regarding the MOUs, CPHHP sent initial drafts to DDS, DSS, SDE and UCHC contracts office. Drafts were modeled after those in development for the P20Win initiative and existing MOUs for CHIN. State agency response times varied substantially, with SDE providing comments in seven days, DDS in 60 days, and no comments from DSS to date (46 days).

Once CPHHP received initial comments from SDE, the draft MOU language was revised. All draft MOU language for the demonstration project was forwarded to the UCHC contracts office in early February 2013 and an update with DDS' comments was sent in March. It is the understanding of CPHHP that UCHC contracts office has not finished their review and revisions to the language. It is unclear whether UCHC contracts office has engaged in discussions with SDE, DDS or DSS. CPHHP initiated the MOU process at UCHC more than 60 days ago and has not received confirmation of its status despite multiple attempts to do so.

<sup>2</sup> Email correspondence from Diane Aye dated 4/4/13.

<sup>3</sup> Email correspondence from Anne McIntyr-Lahner dated 4/5/2013.

## Summary

Acquisition of data from Connecticut state agencies is a difficult and time-consuming process. The coordinated acquisition of data from *multiple* state agencies, which is generally required to address critical policy questions related to Connecticut's neediest and costliest residents, is Sisyphean. This system cannot be allowed to persist if Connecticut intends to make effective use of the data it collects to drive decisions in delivering better and more cost effective health, social, and educational services to its residents. Suggested improvements to the current process for obtaining data from agencies include:

- Streamlined contracting and IRB processes for data access and exchange;
- Better documentation of the data that agencies collect and maintain;
- Making data dictionaries publicly available and publishing them on agency websites;
- Developing coordinated systems of governance that facilitate appropriate access to and use of agency data.

Although the development of an Office of Early Childhood will address some of these problems by consolidating some early childhood data within a single agency, more efficient and robust protocols for data sharing will still be needed to allow the new agency's systems to connect to other systems that will not be included in its warehouse (for instance, DSS/Medicaid and the All Payer Claims Database). Fortunately, several of these improvements are currently being operationalized to facilitate the deployment of both the Connecticut Health Information Network and the P20 WIN network, which include many of the agencies sitting on the Early Childhood Education Cabinet. The Cabinet is encouraged to capitalize on these resources in developing a plan to address the barriers to data sharing among state agencies.

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