Department of Health and Human Services
Maine People Living Safe, Healthy and Productive Lives
Paul R. LePage, Governor
Mary C. Mayhew, Commissioner

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February 24, 2014

Senator Margaret M. Craven, Chair
Representative Richard R. Farnsworth, Co-Chair
Joint Committee on Health and Human Services
#100 State House Station
Augusta, Maine 04333-0100

Dear Senator Craven and Representative Farnsworth:

In response to your recent request for a comprehensive tracking data system, please find the attached summary of this work prepared by the Maine Developmental Disabilities Council.

Please feel free to contact me if you have any questions or concerns.

Sincerely,

Mary C. Mayhew
Commissioner

MCM/klv

Enclosure

Maine Developmental Disabilities Council

Autism Act Report—Report Back to Commissioner Mayhew on Recommendation to Develop Plan to Implement Universal Screening Tracking System

Submitted by Nancy Cronin, MA, Executive Director

January 10, 2014

Purpose

In June 2013, the Health and Human Services (HHS) Committee sent you a letter requesting a plan to implement a comprehensive tracking data system, with a report back in January 2014. Last July, in response to that request, you authorized the Maine Developmental Disabilities Council (DD Council) to facilitate a meeting of information technology professionals to discuss the data systems collecting child data that exist in Maine and identify possible ways to improve connections between those systems and electronic medical records.

Review Methodology

Your directive included the provision that I ensure the inclusion of other initiatives in this project, an approach I both shared and employed. On December 3, 2013, the first Child Development-Information Technology Data Systems meeting was hosted by the Maine Developmental Disabilities Council at Maple Hill Farm from 11 a.m. until 2 p.m. A total of twenty-two (22) data technicians and systems experts participated in the meeting. The meeting allowed technicians to meet one another and learn more about the systems in which they work. Further, the technicians began examining the existing data systems and data sets that would be important to the health and well-being of children in Maine.

Meeting Findings

The outcome of the meeting was the clear need for a high-level data base inventory to gather information about the multiple data systems that collect information about the health of Maine's children and the public services they use. As you noted, there are already projects occurring aimed at improving how we collect data regarding children. However, a high-level inventory could be valuable. This inventory would result in a report that educates Maine policy makers and stakeholders about current information technology systems within the Departments of Education (DOE) and Health and Human Services (DHHS) that collect child developmental health data, identifies opportunities for connectivity between specific data sets and recognizes the barriers that exist which can impede connectivity. The questions for this inventory have been developed and those attending the meeting on December 3 were asked to complete it.

The Maine Developmental Disabilities Council also recognizes the impact this work will have on the Developmental Systems Integration (DSI) work that is currently being conducted by Maine Quality Counts in partnership with the Maine DHHS. The DD Council is committed to working with staff at Maine Quality Counts to get their input on the inventory, analysis, and the final report. Ideally, the document will be ready to assist the DSI Project with their May meeting to analyze data systems collecting screening information on young children. Further, once the inventory is created, we will request that the information technology professionals gather to analyze the document and discuss potential steps to recommend connectivity options.

Next Steps/Recommendation

The DD Council is committed to providing some staffing and funding towards this goal. Specifically, I will be overseeing the work and collaborating with the DSI Project. The DD Council will fund a staff person for eight (8) hours per week to assist us with the inventory. The DD Council will also sponsor the meeting of professionals this spring and ensure that basic materials for the project are covered. The total value of that is approximately $9,000. I am happy to say that the DSI Project is also willing to assist with development of the inventory using an existing contract with the Department to promote a the State Agencies Interdepartmental Early Learning Team (DOE/DHHS SAIEL) objective to improve coordination across state agencies to support young children's optimal development. The value of that assistance is $2,500. Our intent is to avoid additional Department costs. I have written a grant to the Association of Maternal and Child Health Programs (AMCHP) that, if funded, would mitigate some of the expense. While I am optimistic at our chances of a grant award, even if we do not receive the external funding, the DD Council can absorb the work into this year's budget.

While this plan may not be as comprehensive as the HHS Committee wanted, it does provide the necessary first step in understanding and linking our multiple State data sets.

I look forward to hearing your thoughts about this idea. If I could be of further service in fulfilling the HHS Committee request, please do not hesitate to ask.