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Senator Rafferty
Representative Brennan
Members of the Educational and Cultural Affairs Committee

RE: LD #'s 135, 255, & 386

Dear Senator Rafferty, Representative Brennan and other distinguished members of the Educational and Cultural Affairs Committee,

My name is Sue Mackey Andrews and I live in Dover-Foxcroft. I moved here in 1979 to start what was then, the 7th site to provide coordinated services to children ages 0-5 with developmental delays in Maine. Five years later, I moved to the DOE to direct this 0-5 interagency system for nearly ten years during the creative of P.L. 99-457 and its implementation in Maine. For the next 22 years, I provided consulting services to 48 states and territories, including Puerto Rico, in the development of Part C services. This work included the development and implementation of Central Billing Office (CBO) systems, development of a variety of interagency agreements as required by the Federal Part C of IDEA, ensuring interagency financing for these services and creating monitoring and supervision systems to ensure the quality of services and supports including, importantly, professional development.

Thank you for your service to our State and, to our children and families. Yours was never an easy task, made only more challenging during this Pandemic.

Each of these three bills is basically "empty" which makes it difficult to respond in a meaningful way to what is proposed. I am submitting comments based upon what I heard after listening to several of your committee discussions about CDS and several presentations made by the DOE CDS staff. I remain very concerned about the quality of care provided for very young children and their families when children are experiencing developmental delays or disabilities and are age 0-5.

I believe strongly that consideration to move the Lead Agency to DHHS should happen. The overwhelming majority of programs, services and funding for the 0-4 population are located in DHHS and coordination, interagency agreements, comprehensive case management, and payor of last resort – all as required by federal law – would happen. Our State DHHS Medicaid agency has one of the most comprehensive data systems in the country and could handle Central Billing functions in a heartbeat.

I highlight other comments in the sections that follow.

Oversight during Transition

One of the items that should be included in the legislation re: CDS is the role of the ICC and the importance of independence from the DOE in realigning this committee to really make sure that it works. Currently both the ICC and the committee overseeing 3-21 special education are managed by the DOE and informed and directed by them. This was not the intention of federal law!

Part C is a federal law requiring interagency collaboration and coordination – it was never meant to “belong” solely to one state agency. Its foundation is in blended funding, shared services and coordinated administrative functions such as case management, ChildFind and transition.

Some states, for example, have independent directors for their ICCs, reporting directly to the Chairs, etc., which ensures this independence and that the committee can actually get the work done with what is essentially a group of volunteers. These directors communicate with other state agencies, oversee the implementation of interagency agreements (a federal requirement of many subjects), and work to implement the 16 requirements of the federal law.

To support this transition of CDS in a meaningful and transparent way, one that hopefully will resolve the current series of problems and lack of compliance, a Transition Oversight Committee that directly reports to you – the Educational and Cultural Affairs Committee – composed of a variety of learned persons not involved in the provision of direct services at the current time including CDS must be appointed. This Transition Oversight Committee would be informed by the DOE, SAUs, public and private providers and the other state departments who also have interest and investment in the provision of services to this population. It would be time-limited – perhaps 3-5 years depending upon the progress of the DOE and others to implement identified systems changes and improvements.

Eligibility

We are all agreed, I believe, in the following facts related to Part C:

- Maine has one of the most restrictive eligibility criteria in the country for this population
- Maine serves the fewest number of infants and toddlers in the country under our Part C system (See Attachment A)
- The annual count for Part C averages 850-950
- Of the total referrals to Part C, fewer than 35% are determined eligible. This chart is from the CDS report to the Legislature, 2019.

(a) *The number of children referred to the Child Development Services System in the prior year by referral source, including the screening programs in Title 22, sections 1532, 8824, and 8943, and the percentage of children referred found eligible for services:*

Calendar Year 2018	Ages Birth - 5	Ages Birth - 2	Ages 3 - 5
All Referrals	8,266	3,322	4,944
Found Eligible	3,079	1,130	1,949
Percent Found Eligible	37%	34%	39%
* referral date 1/1/2018 – 12/31/2018			

These eligibility figures present several questions about the efficacy of the CDS system overall – but minimally, they do confirm that:

- Current CDS eligibility is not well understood by referrants and the lack of eligibility for the bulk of referrals is hardly reinforcing to promote more or continued referrals
- There are a lot of children with at least perceived needs by the referral source (largely physicians) who are going unserved or, at the direction of their Primary Care Provider (PCP), then referred to the “medical model.”

- Because of the process that CDS follows upon referral, where they provide a multidisciplinary assessment for every referral -significant funds and personnel are wasted when there are other approaches to determining eligibility and identifying needed services.

The final legislation needs to insert a requirement that eligibility is examined with the consideration to expand eligibility beyond what current exists.

Disposition of Three Year Olds:

I feel strongly should be in a Part C option which provides for a 0 to 4 system in Maine. This would ensure several things:

- Comprehensive statewide implement of 4 and 5 year old regular and special education services for all Maine children. Districts are at different places with varying capacities both from a personnel and physical plant perspective. During the Pandemic, we have lost many good programs which need to be restored locally. All of this will take time.
- Parent would be given a choice at transition time (2.6 years of age) as to which system they want for their child. Remaining in Part C would mean basically staying in the same service delivery system, same eligibility and same providers.
- Adding the 3 year olds to CDS would provide *greater economies of scale* to CDS by adding more children to their overall caseload, even under the current eligibility criteria.
 - I fear that with our declining child population coupled with the restrictive eligibility criteria currently in place, Maine will be unable to sustain the infrastructure in a defensible way financially. You at this table will be back in 2-3 years having this discussion yet again, I believe, if we don't examine the whole picture together.

I know full well that these 3 year olds would need to be Part B eligible to stay in either program. I understand that the DOE has said that very few of them would be eligible for Part B. I have to ask – **don't you find that incredibly sad and irresponsible?** Part C is not only a treatment program, it also is tasked with prevention.

The Part B eligibility is not appropriate for most very young children and the definition of DD is left to the SAU including whether or not to even include children with developmental delays at all. Fewer children served in this example is not a good thing, especially since we can't "catch up" developmentally for the time and opportunities lost.

- The criteria for developmental delay in both Part C and Part B/619 should be revisited and changed from "significant delay" to one more inclusive with a prevention approach, rather than leaving these young children totally unserved.

Contracting vs. Employees

This is an old issue that as you know percolates every once in a while. The root issue is control – s has been verbalized by the DOE: making sure that providers 1) meet the timelines required and 2) most especially, to control the amount of services to some level that has been developed rather than using individual needs, respecting the role of the IFSP/IEP Team recommendations, etc.

- The "primary coach model" used in Part C broadly for all kids results in lower costs for kids at CDS but escalates the costs at MaineCare, DHHS/OBHS and a family's private insurance when physicians and families believe additional service(s) is needed. These additional services are typically not in the IFSP/IEP and too often not coordinated together with CDS services. Many of

these children are also referred to DHHS/OCBH and receive additional services through this program which are often not closely coordinated.

Monitoring and Supervision

A few thoughts on the issues that emerged during the recent discussion with the Committee and DOE focused on DOE now as the provider (through their employees) for Part C services and also the monitor of said services. This conflict of interest is quite apparent to most of us; sort of like the "fox and the hen house."

- The same people who are hiring, supervising and setting the rules for Part C are turning around and monitoring said services provided by their own employees.
- Because Part C requires "payor of last resort," the CDS or whomever is lead agency for Part C is required to honor the requirements of other funding sources - e.g., most particularly Medicaid and the utilization of these funds. Medicaid requires provider choice of services which doesn't happen typically in the current CDS model and most certainly would be impossible in a total CDS/DOE employee-based service delivery system.
- Part C requires that families have the ability to agree to the use of their insurance - public OR private. A family can deny access to either or both regardless of how much sense denying access to Medicaid might make.
- "Owning" most of the CDS employees permits the current CDS to require them to implement the decision-making limits on services, provider selection and model of primary coach model regardless of individualized needs of the child or family.
- Under the DOE owned model, different from the public schools where they are a provider and the DOE provides oversight, monitoring and due process - DOE would now be providing all three functions for their own employees/system and the families it serves.
- If CDS is permitted to manage CDS, hire all of the employees/providers etc. then there should be a third party doing the monitoring. It is only proper and fair for families and providers!

Thank you for listening. I plan to attend the work session is available and would be happy to answer any questions. If a Transition Oversight Team is created, I would be happy to serve on this Team.

Sincerely,



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IDEA Part C

Percentage of all children under the age of one receiving services by Eligibility (Single day count 10/1/-12/1/2018)

— = 1.25 national average

█ = Birth Mandate

█ = At risk

59% of Category A states meet/exceed the national average
 56% of Category B states meet/exceed the national average
 25% of Category C states meet/exceed the national average

Category A Eligibility (17)

New Mexico	4.02
Pennsylvania	2.70
Vermont	2.06
Kansas	2.00
Washington	1.95
Maryland	1.68
Virginia	1.58
District of Columbia	1.37
Colorado	1.29
Michigan	1.27
Iowa	1.18
Texas	1.09
Wisconsin	1.04
Hawaii	0.85
Delaware	0.83
Alabama	0.69
Arkansas	0.62

Category B Eligibility (18)

Massachusetts	5.05
West Virginia	3.30
Rhode Island	3.14
Wyoming	3.00
New Hampshire	2.38
North Dakota	2.35
Indiana	1.63
Illinois	1.42
South Dakota	1.40
Tennessee	1.38
North Carolina	1.15
Nebraska	1.09
New York	1.08
Utah	1.05
Ohio	0.99
Minnesota	0.93
Mississippi	0.92
California	0.63

Category C Eligibility (16)

Alaska	1.71
Idaho	1.57
Louisiana	1.52
Missouri	1.35
Montana	1.24
Connecticut	1.19
Nevada	1.08
Oregon	0.98
South Carolina	0.98
Arizona	0.92
Oklahoma	0.83
New Jersey	0.81
Georgia	0.80
Florida	0.71
Maine	0.60
Kentucky	0.54

Category A: At Risk, Any Delay, Atypical Development, one standard deviation in one domain, 20% delay in two or more domains, 22% in two or more domains, 25% delay in one or more domains.

Category B: 25% in two or more domains, 30% delay in one or more domains, 1.3 standard deviations in two domains, 1.5 standard deviations in any domain, 33% delay in one domain.

Category C: 33% delay in two or more domains, 40% delay in one domain, 50% delay in one domain, 1.5 standard deviations in 2 or more domains, 1.75 standard deviations in one domain, 2 standard deviations in one domain, 2 standard deviations in two or more domains.

Notes:

- The percentages reflect the total count including at-risk
- States self declare the category that most closely aligns with their eligibility criteria
- Eligibility categories were established by the ITCA Data Committee as of 2010.

Sources: U.S. Department of Education, EDFacts Metadata and Process System (EMAPS): "IDEA Part C Child Count and Settings Survey," 2018. Data extracted as of July 10, 2019. U.S. Bureau of the Census. "2018 State Population Estimates by Age, Sex, Race, and Hispanic Origin". Data accessed July 2019 from <http://www.census.gov/popest>