Maine Developmental Disabilities Council

January 11, 2024

Testimony in **Oppose** LD 779 An Act to Create a Separate Department of Child and Family Services

Senator Baldacci, Representative Meyer and the distinguished members of the Committee on Health and Human Services:

My name is Nancy Cronin, and I am the Executive Director of the Maine Developmental Disabilities (DD) Council.[1] I am here to testify in opposition of LD 779. The Council is not so much opposed to the idea of a new Department for Child Welfare as we are concerned that the make up of the proposed Department is inappropriate and will not help children with disabilities. The child welfare system has many problems. But separate from those problems is the reality that the current oversized OCFS has many children who are not served and are lost to the system. These issues that are happening around children and youth with disabilities have different origins and different solutions than the issues around Child Welfare. Let me explain.

Many years ago when the Department of Human Services merged with the Department of Behavioral Health children with intellectual disabilities and/or autism **WHO HAVE** Challenging Behaviors were swallowed into a new Office that included Mental Health and Child Welfare. This is the origin of OCFS.

Other children with special healthcare needs were pushed aside to the Centers for Disease Control and Prevention within the Maternal Child Health Program[2]. A few years later the Children with Special Healthcare Needs was further demoted deep into the bowels of population health. Many of the positions needed to serve these children, such as a medical

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[1] Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970.ThereThere has bee Maine's DD Council has been advocating with and for individuals with developmental disabilities for over 50 years. The DD Council is a federally funded, independent organization with members from across the state, including persons with disabilities, family members, and representatives of public and private agencies which provide services and/or funding for services for individuals with developmental disabilities. As required in federal law, we are involved in advocacy, capacity building and systemic change activities, with the goal that individuals with developmental and other disabilities of all ages are fully included, integrated, and involved in their communities and the decisions impacting their lives.

[2] Note: According to Social Security Administration MCH and Children with Special Healthcare Needs programs must be in the State Health Agency https://www.ssa.gov/OP_Home/ssact/title05/0509.htm

director, was completely eliminated. I don't know exactly where the 30% of the Title V block grant required to serve Children with Special Healthcare Needs has gone but it is not being used to serve these children. There are a few child programs that remain such as the cleft lip and pallet, genetic or newborn hearing programs. But children with special healthcare needs that do not have challenging behaviors have no program and nobody at the Department charged with tracking their needs. They are simply invisible.

Children with Developmental Disabilities include medically fragile children, children with physical disabilities like Cerebral Palsy, young children with developmental delays, children with special healthcare needs (like children with ADHD who takes four or more medications or children with seizure disorders), and children with intellectual disabilities or Autism Spectrum Disorders. I am going to call all these children, children with Developmental Disabilities.

There are very few ways that a child with a developmental disability can access services through DHHS unless they begin exhibiting challenging behaviors or have a clear mental health condition. Even though Title V is for all children with special healthcare needs regardless of Medicaid eligibility, families cannot even access case management. It is only when children's needs have not been met and the child starts behaving in challenging ways that families might be able to get help. That is, if the family and child can find themselves eligible for MaineCare. Only then can they access help through the <u>Behavioral</u> Health or Mental Health service structure.

This is simply backwards. The Adult system has an Office of Developmental Disabilities where adults with physical disabilities such as Cerebral Palsy can get help. The Office of Developmental Disabilities also supports adults with Intellectual Disabilities and Autism Spectrum Disorders so they can successfully live in the community. The adult system also has an entire other system of care to support adults with mental health. And lastly, the adult system supports people in our communities aging.

Why doesn't our children system do this? Why do children have to behave in difficult ways to get their needs met? Children with disabilities can receive intervention at much lower acuity levels and that intervention can prevent challenging behaviors. This will reduce the need for residential help and stuck kids in emergency rooms.

Maine does have a robust effort to screen and identify children with disabilities. We have put excellent resources into screening and evaluation through our Maternal Child Health program in the CDC or Help Me Grow, currently located in the enormous OCFS. But once identified there is nothing to support the development of those identified children with disabilities. This is despite our receiving Title V Children with Special Healthcare Needs funds which is supposed to care for all these children despite eligibility to Medicaid. Instead we demand a pipeline into Mainecare where they can receive behavior support for their challenging behavior.

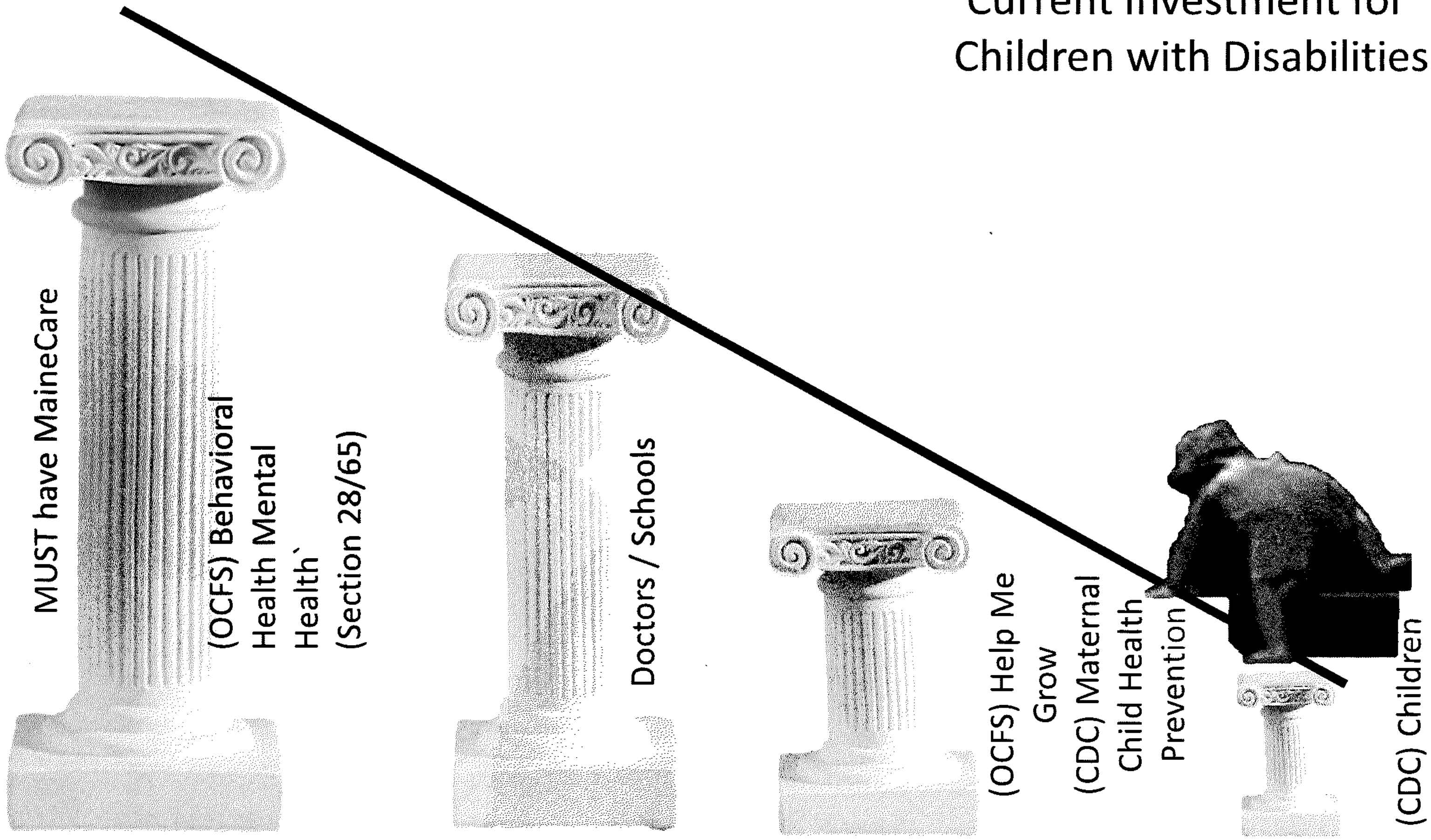
We don't look at the child with Cerebral Palsy or Downs Syndrome as a child that needs potential intervention to support their development. We don't support successful development as we support successful aging. We wait until the child is so desperate that they exhibit challenging behavior.

Children with disabilities have been lost in our system. I propose creating a true Children with Special Healthcare Needs Office within DHHS. I would support a Department of Child Welfare – that job is very different.

I do hope to provide national expertise on the role of Children with Special Healthcare Needs to the Blue Ribbon Commission to Study the Organization of and Service Delivery by the Department of Health and Human Services. We need an elevated program to coordinate and advocate for supported development to children with special healthcare needs.

Thank you for this opportunity to provide input and I am available for any questions.

Current Investment for Children with Disabilities



Other Systems

Child with Disabilities May need other systems like Child Welfare but this is not specific to disability – it is specific to maltreatment

MUST have MaineCare

(OCFS) Behavioral Health Mental Health` (Section 28/65)

Reactive Treatment
Challenging Behaviors / Something Went Wrong

Doctors / Schools

Evaluation / Diagnosis

(OCFS) Help Me Grow

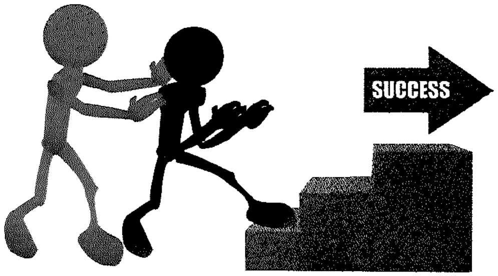
(CDC) Maternal Child Health Prevention

Screening / Public Health

(CDC) Children with Special Healthcare Needs

Developmental Support
Proactive Development

Proposed Investment for Children with Disabilities



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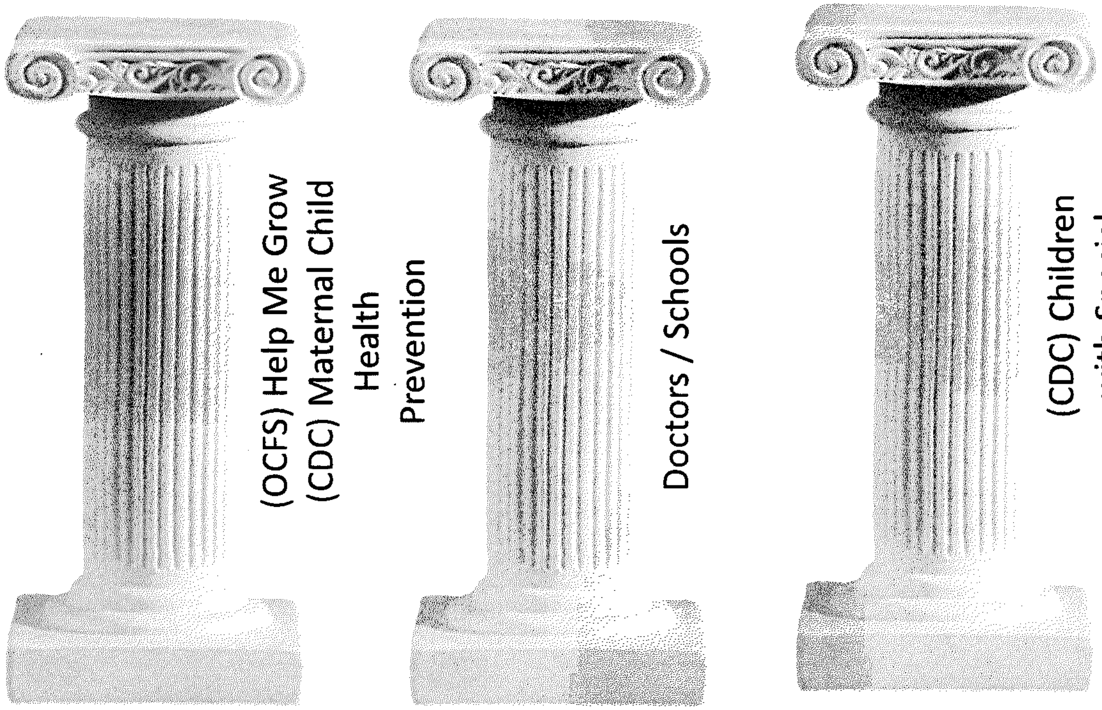

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Prevention

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(CDC) Children with Special Healthcare Needs

Support
Proactive Development

(OCFS) Behavioral Health Mental Health
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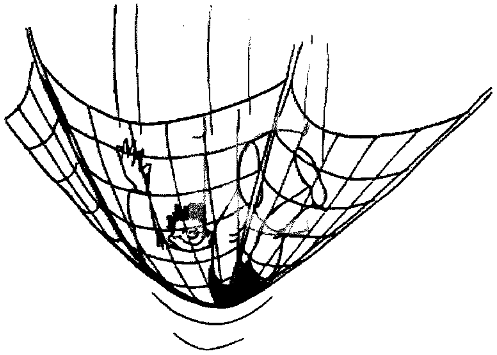

Reactive Treatment
Challenging Behaviors / Something Went Wrong