



Maine Developmental Disabilities Council

March 16, 2021

Testimony Neither For Nor Against LD 529, “An Act To Restore the Maine Center for Disease Control and Prevention Cystic Fibrosis Assistance Program”

Senator Claxton, Representative Meyer and the distinguished members of the Joint Committee on Health and Human Services.

My name is Nancy Cronin and I am the Executive Director of the Maine Developmental Disabilities Council (DD Council)¹. I stand neither for nor against this bill because it focusses on just one population of Children and Youth with Special Healthcare Needs (CYSHN) when there are many children, youth, and families with low-incident health conditions in need of the CDC’s attention and money. Cystic fibrosis is one of these low-incident health conditions, but there are others such as Cerebral Palsy, Lowes Syndrome, Muscular Dystrophy, spina bifida, chromosomal disorders such as Downs Syndrome, neurological disorders, and many more.

Maine receives Title V, Maternal, Child and Family (MCF) federal block grant dollars. A significant portion of the block grant is to go to the CYSHN Program. In most State’s that program is elevated to represent all CYSHN across all public service systems. Unfortunately, recent years found that the CYSHN program was demoted to a lower office in the CDC. Also, unfortunately and historically, the Maine CYSHN program was divided into specific disability programs as opposed to focusing broadly across the

¹ Councils on Developmental Disabilities were created through the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) in 1970. Maine’s DD Council has been advocating for individuals with Developmental Disabilities (DD) for over 40 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 law¹, our purpose is to promote systems change to ensure that all individuals with developmental disabilities are able to live and fully participate in their communities of choice. Working in partnership with people with disabilities, parents, advocates, and policy makers, Maine’s DD Council works to promote the independence, integration, and inclusion of all people with disabilities through advocacy, capacity building, and systems change activities throughout the state of Maine and on the national level. The DD Council’s mission is **to create a Maine in which all people are valued and respected because we believe communities are stronger when everyone is included**. The Maine DD Council employs four full-time staff who are responsible for all of the internal projects, external grants, and business of the Council.

overall system to ensure representation across programs, quality healthcare and care coordination for all CYSHN. The funding has been doled up in turns, a portion of funding and attention goes to cleft-lip and pallet program, another portion of funding and attention goes to the newborn hearing and screening program, still another... you get the picture. Unfortunately, this systemic practice left out the other children with special healthcare needs creating a group of children we served with these block funds and a group we didn't. This is contrary to what Title V MCF block grant funds are supposed to do.

It is not that I don't believe that children and youth with cystic fibrosis need help. They do. But we don't have the resources to divide among every low-incident disorder and it is not fair to create a public health system that only serves some of the CYSHN. We need to invest money smarter and in a way, that represents the needs of all CYSHN, including those with cystic fibrosis, and cerebral palsy, and spina bifida, and Lowes Syndrome, and the rest.

I thought about opposing this bill but decided that this issue doesn't need to go away but instead it needs to be evaluated. Please consider changing this bill into a legislative vehicle that would include a report back to you next session that identifies common low-incident CYSHN disabilities, describes these children and youth's unmet needs, and provide recommendations to improve the CYSHN Program so that those children's needs can be met.

I appreciate the opportunity to speak with you today and would be happy to take any questions.