



Service Reforms for Children with Intellectual and Developmental Disabilities

Maine families with children who are diagnosed with intellectual and developmental disabilities are currently not able to access the community services that they need. There are long waitlists for basic support services which has led to children being inappropriately hospitalized, institutionalized, incarcerated, homeless, and sent out of the state. Repeated cuts to reimbursement rates for community-based services have further led to a shortage of providers and additional waitlists even after funding for services is authorized.

Children's Behavioral Health Services

There are multiple waitlists overseen by OCFS listing hundreds of children with developmental and mental health disabilities who are waiting for Section 28 and 65 services. These waitlists exist due to a shortage of providers and represent children who are unable to access any of the support services they have been determined eligible for. The waitlists must be eliminated in conjunction with the creation of waiver services for children with IDD.

a. Children with Intellectual and Developmental Disabilities

There are no community-based services designed specifically to meet the needs of children with IDD. The Department of Health and Human Services ("the Department") promulgated regulations to begin providing specialized services for children with IDD in 2011¹. However, the reimbursement rate was set so low that providers were unable to deliver the service. The Department withdrew the regulations and discontinued the service in 2015 without serving a single child.

Recommendation: Establish a home and community-based waiver for children with IDD with a rate which supports the services children are determined eligible for.

b. Psychiatric Residential Treatment Facilities

The Department promulgated regulations this year to establish new institutions, Psychiatric Residential Treatment Facilities, for children with disabilities. These institutions were created with the stated intent of providing services to children incarcerated, stranded in psychiatric hospitalizations and emergency rooms. However, because community support services are unavailable, it's unclear whether an institution is the least restrictive environment for these children.

¹ Previously, 10-144 Chapter 101, MaineCare Benefits Manual, Chapter II and III, Section 32, Waiver Services for Children with Intellectual Disabilities or Pervasive Developmental Disorders

Recommendation: Establish a home and community-based waiver for children with IDD and fund the remaining waitlists prior to approving new institutional services.

Non-Emergency Transportation

The current brokerage system for providing Non-Emergency Transportation fails to provide consistent and appropriate transportation and has had a significant and disparate impact on children with disabilities. Vehicles are not adapted or fitted with car seats and other equipment necessary to transport children with disabilities. Further, children are being transported with adult recipients and left unattended in dangerous situations where they are at risk for abuse, neglect, and exploitation.

Recommendation: Require specific training and background checks for Non-Emergency Transportation drivers transporting children with disabilities and allow direct billing for current Section 28 and 65 providers to provide Non-Emergency Transportation to Section 28 and 65 services.

The Maine Association for Community Services Providers (“MACSP”) is the statewide association of organizations providing supports and services for Maine children and adults with intellectual and developmental disabilities (“IDD”). MACSP’s membership is dedicated to ensuring Mainers with IDD have access to the support they need to live and thrive in the community. Our mission is to provide high quality services in the least restrictive and environment and support Maine people to avoid unnecessary institutionalization.