



Service Reforms for Adults with Intellectual and Developmental Disabilities

Due to a lack of enhanced behavioral supports, adults diagnosed with intellectual and developmental disabilities (“IDD”) are inappropriately hospitalized, institutionalized, incarcerated, homeless, and sent out of state. The lengthy waitlist for Section 21 services is prioritized by need for Adult Protective Services, leaving adults with IDD without the support they need until abuse, neglect, or exploitation has occurred. The Department of Health and Human Services (“the Department”) has lost capacity to provide adequate crisis services to intervene creating an overreliance on hospitals and institutions to serve as crisis support.

Crisis Services

Crisis Services, specifically identified in Maine statute to prevent inappropriate placement in hospitals or jails¹, currently lacks the capacity to intervene to support adults with IDD in crisis. There are currently four (4) crisis homes intended to cover the entire State which are consistently unavailable. Crisis workers are used to staff those homes and therefore unable to meet with or respond to individuals who call the crisis hotline. Though there are eight (8) placements across the four (4) homes, there are constructively less as some homes can only accommodate staffing for one (1) member at a time.

Recommendation: Promulgate regulations to govern Crisis Services which establish and support capacity benchmarks, data collection, and training.

Adults with Behavioral Needs

Section 21 and 29 services do not include specialized and individualized support for individuals with high behavioral needs. This includes environmental adaptations, consistent and specified staff training, and clinical support and oversight. These services and support have been cut and/or so greatly reduced that individuals with behavioral needs are unable to find support in the community.

Recommendation: Expand Section 21 and 29 services to include enhanced services and associated funding for individuals with high behavioral needs.

Office of Inspector General Report

In August of 2017, the Office of Inspector General (“OIG”) issued a report with findings that the Department did not investigate thousands of reports of abuse, neglect, exploitation, and deaths of Mainers with IDD. In January of 2018, the OIG jointly with the Administration for Community Living

¹ 34-B M.R.S. §5206 *et seq*

(“ACL”) and the Office for Civil Rights (“OCR”) issued recommendations and model practices for ensuring health and safety for beneficiaries of Developmental Services. The Department has not promulgated regulations or established rules consistent with those recommendations.

Recommendation: Integrate the OIG’s joint recommendations into our current Adult Protective Services and Reportable Event regulations, including recommended model practices for incident management and investigation, incident management audits, mortality review, and quality assurance.

Non-Emergency Transportation

The current brokerage system for providing Non-Emergency Transportation fails to provide consistent and appropriate transportation and has had a significant disparate impact on adults with IDD. Adults with IDD are routinely denied transportation to medically necessary services without notice because brokers are unwilling to provide necessary and reasonable accommodations. This further puts adults with IDD in dangerous situations where they are at risk for abuse, neglect, and exploitation.

Recommendation: Require training and background checks for Non-Emergency Transportation drivers transporting adults with IDD and allow direct billing for current Section 21 and 29 providers to provide Non-Emergency Transportation to Section 21 and 29 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.