

Report from ILLINOIS

By Rita Winkeler, State of Illinois Coordinator

The census of the State Operated Developmental Centers (SODCs) in Illinois has remained stable for the past five years. The state SODC census ending April 30, 2018 was 1,666. The census as of May 1, 2019 was 1,672. The state has moved some individuals from the SODCs to private ICFs or Community Integrated Living Arrangements (CILAs- group homes), but as they have moved residents, other individuals have taken their place in the SODCs. Private providers in Illinois have now made it very clear to the state that they will not provide services for the most seriously behaviorally challenged individuals as they do not have the resources to provide proper care for these individuals. This refusal to provide services is in part due to the Chicago Tribune series of articles about the lack of oversight of the CILAs in Illinois, and to the Attorney General of Illinois's audit of the CILA system in Illinois (July 2018) which showed a large amount of abuse/neglect, and a lack of oversight in the community system. Providers do not want to be held accountable for abuse/neglect, and have the right to refuse services to disabled individuals who seek services in their homes.

Murray Center, where our son resides, has had twenty admissions in the past ten months. All of these but two have come from failed CILA placements. In the past four years 50 residents have been admitted to the center. The seven state-operated developmental centers have admitted over 80 individuals in the past year.

Currently, over 24,000 Illinois disabled individuals are serviced through the Division's Medicaid Waiver program. At this time, there are over 24,000 on the Prioritization for Urgency of Need for Services (PUNS) List – disabled individuals waiting for services. There is a 5-7 year wait before receiving services under the Medicaid Waiver Program. The *Ligas v. Hamos* lawsuit, was filed on July 28, 2005, on behalf of adults with developmental disabilities living in private, state-funded Intermediate Care Facilities for Persons with Developmental Disabilities (ICFs/DD) who want to move to community-based services or settings and on behalf of adults with developmental disabilities living at home who want community-based services or settings. In June 15, 2011, the *Ligas v. Hamos* Consent Decree was approved by the Court. The goal for this year is to move 600 disabled individuals from ICFs to smaller community homes. It has proven difficult for the Department of Human Services to move the required amount of residents from ICF placement to community placement each year, as parents/guardians are refusing to move their wards, as they prefer ICF services instead of community services. Under the *Ligas* Consent Decree guardians have a right to refuse community services, and continue ICF services. At this time there are over 200 private ICFs with the capacity for over 4,500 residents. Most of these homes are not filled to capacity, and many have converted from ICFs to smaller CILA homes.

Funding in Illinois for all DD/ID services continues to be a constant struggle. The minimum wage in Illinois has risen to \$15 an hour, and the hope is that this raise in wages will help elevate the lack of Direct Service Personnel. A new Governor was elected in 2018, and new Department of Human Services administration has been put in place, but it is too early to see if there will be any significant changes in the care of the disabled in Illinois.