

Illinois Intellectual and Developmental Disability Services Priorities January 2020

Below are some characteristics of the Illinois service system for people with intellectual and developmental disabilities:

- Illinois ranks 47th nationally in both fiscal investment in community services as well as investment in services that promote community inclusion
- Illinois ranks 2nd nationally in census for large, public state institutional settings; 14 states, including neighboring Michigan and Indiana have no public institutions and 13 additional states have fewer than 200 people residing in such settings
- Illinois has been found out of compliance with the Ligas Consent Decree since 2015
- When the CILA program began, state reimbursement for the average (not minimum) DSP wage was 93% more than minimum wage. Effective 1/1/20, the statewide differential has dropped to 28% with reimbursement for average (not minimum) DSP wages in Chicago below the mandated minimum wage of \$13/hour.
- Average reimbursement for people in community residential settings (CILA) is only 20% of average reimbursement for people in state institutions, with no credible data to support the presumption that people in state institutions have greater support needs.

The Institute on Public Policy for People with Disabilities is working to enhance, expand and evolve the Illinois community system for people with intellectual and developmental disabilities; we value the opportunity to partner with stakeholders who similarly envision a future where all people with disabilities have access to services and resources to pursue meaningful and valued lives. Below we highlight several pivotal topics impacting Illinoisans with I/DD and the organizations that support them, as we embark upon a new decade.

Equity for People in Community I/DD Services

The Institute has raised the issue of the inequity of the community I/DD system compared to resources available to people in state institutions throughout 2019 and will continue to focus on this issue throughout 2020. Research conducted by the Institute this past year confirmed that people living community settings have significant support needs that, based on publicly available data, vastly exceed the support needs of people living in state institutions. Despite the intensity of support and supervision needs for people in community settings, average reimbursement for these services is only 20% of reimbursement for services in state institutions. Some highlights from our research include:

- 27% of CILA residents are age 60+ reflecting the likelihood of needing greater supports in the areas of healthcare and mobility as well as the possibility/likelihood of experiencing or acquiring dementia (“Epidemiology of Dementia and Alzheimer Disease in Individuals with Down Syndrome” found 52% of adults with Down Syndrome age 55+ also have a dementia diagnosis)
- 40% (N=4,292) of CILA residents’ support and supervision needs are classified as requiring “Total Care/Intense Supervision or Extensive Care/Constant Supervision”. This subset is 2 ½ times larger than the **entire** SODC census; even if every person in a state institution had a similar support needs profile (which is not reflected in the data), the community system would still be supporting thousands more people with extraordinary support needs than live in state institutions, at 20% of the average reimbursement for state institution services
- The average annual Medicaid reimbursement for all I/DD state institutions in Illinois is \$284,413/person/year, compared to the average reimbursement for 24/7 CILA settings of \$60,560. Put another way, on a per person basis, Illinois invests 80% more on services for people in state institutions than it does for people in community settings, despite the clinical data demonstrating a greater need among people living in community settings.

While the discussion regarding Illinois' investment priorities in I/DD services has historically been framed as “rebalancing”, we believe the issue of equity and access to necessary services, supports and resources should be the lens through which difficult policy decisions regarding the Illinois I/DD system should be made. There is simply no rational argument to support the current disproportionate investment in state institutions when neither the clinical need, nor the empirical evidence supporting that service model, exists.

Ligas Oversight Committee

The Ligas Oversight Committee was established to provide guidance and recommendations to the state in complying with the Ligas Consent Decree. In 2019, the state contracted with Navigant Consulting to conduct a rate study in accordance with recommendations from the Oversight Committee. A provider survey is underway with the results expected to indicate the need for greater fiscal investment in community services. It is important to note that the rate study and accompanying recommendations won't be finalized until mid to late 2020 and that I/DD agencies are expressing grave concern regarding the fragility of the community system. Below is the first recommendation submitted by the Subcommittee Chairs to the Oversight Committee and consultants:

“Immediate intervention must be made to stabilize the community system while the complete rate review is being conducted. Critical areas for consideration include staff wages, particularly regarding enhanced Chicago and Cook County minimum wages, as well as 1/1/20 and 7/1/20 statewide minimum wage increases; nursing hours and wages and level of support to people with extraordinary support needs. Committee chairs do not feel the community system can continue to function at current reimbursement levels during the rate review and development period, which at a minimum will continue through 8/1/20.”

Stabilize the Direct Support Workforce

People with intellectual and developmental disabilities depend upon a direct support workforce to provide support, supervision and structure to their daily lives. The stability of this workforce has eroded during the past decade due to stagnant reimbursement rates paid by the state to community agencies, which must compete with other industries that are able to pay competitive wages. When the community system began, state reimbursement for average DSP wages was 92% higher than minimum wage; this differential was an intentional acknowledgement of the critical nature of DSP work and the need to attract and retain a committed and competent workforce. During the past 2 decades that differential has eroded to the point where state reimbursement for average DSP wages is now below **minimum** wage in the city of Chicago and has lost more than ½ the premium it once held statewide.

Effective 1/1/20, the differential between statewide minimum wage and reimbursement for the average (not minimum) wage for DSP will shrink to a 25% differential and effective 7/1/20, only 19%. Community agencies simply cannot compete with other employers whose jobs are better-paying, less demanding and where salaries are sensitive to market forces, rather than state budgetary priorities.

Supporting People to Obtain Employment

Nationally, Illinois has the 2nd lowest workforce participation among people with I/DD receiving community services. In 2016, Illinois convened a public/private sector task force to examine program and funding models that would increase employment opportunities for people with I/DD. Current leadership within DHS and the Division of Developmental Disabilities has committed to expanding resources and options to support people with intellectual and developmental disabilities to obtain and maintain competitive integrated employment at or above minimum wage. The Institute has been involved in these efforts and chairs the provider organization subcommittee of the Employment and Economic Opportunities for People with Disabilities Task Force. Committing resources to expand opportunities for people with disabilities to work in community jobs is essential if the vision of increasing workforce participation among people with intellectual and developmental disabilities is to become a reality.

Emerging Payer Models in I/DD Services Nationwide

In Illinois and nationally, I/DD services remain one of the last fee-for-service payment models in Medicaid and Medicaid HCBS services. As services for other populations move toward capitated, value-based and other payment models, we must assure that any changes to the I/DD funding structure address the unique lifelong nature and philosophy that is the foundation of community services for people with intellectual and developmental disabilities. The Institute has served as a resource in this area for current legislative leaders, national audiences and stakeholders across Illinois, and will continue to inform and educate policy makers in this area. The Institute serves in leadership roles on several state and national efforts including alternate payer models for I/DD service systems, preparing community organizations for success in an alternate payer arena and identifying and measuring quality indicators quality outcomes and measurement metrics for I/DD services that align with value based payment models.

The Institute stands committed to serving as a resource and working in partnership with others who are committed to improving, expanding and evolving services for people with intellectual and developmental disabilities in Illinois.