Balance and Parity for Intermediate Care Facilities
for Individuals with Intellectual Disabilities (ICF/IID)

For some, ICFs are the best setting for care.

- The number of individuals with intellectual disabilities served by ICF/IIDs has halved since 1993. This change means the population currently residing in ICF/IIDs is older and has more severe intellectual and functional impairments and medical conditions. For these individuals the ICF/IID is the least restrictive setting to meet their significant needs.

- Although ICFs serve a very small portion of individuals with disabilities, those individuals deserve the choice to have the level of treatment and quality services provided in an ICF. As important as HCBS is to millions, ICFs are equally important to others. (*See: David Axelrod NYT Op-Ed "When It Comes to People Like My Daughter, One Size Does Not Fit All" (2021)).* Such care is available only for individuals in need of active treatment, which by law refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services. It does cover services for generally independent clients who are able to function with little supervision and who do not require a continuous program of habilitation services. (*42 CFR §483.440*)

- Nearly all ICF residents (97%) are 22 years of age or older. One in 4 residents of publicly-run ICFs are 63 years, or older. More than half (52%) are between 40 and 62 years of age. In general, adults with intellectual and developmental disabilities frequently become frail earlier and develop dementia earlier than the general population, resulting in even higher care needs. Nearly three-fourths (72%) of the residents of publicly-run ICFs have severe or profound intellectual disabilities, meaning the most significant cognitive impairments, than their non-institutionalized cohorts. Some 40% had epilepsy, 19% had autism, and 17% had cerebral palsy. And 56% received medications for mood, anxiety or behavior, or a psychiatric disorder, in addition to their intellectual disability. (*See: Medicaid Services for People with Intellectual or Developmental Disabilities, Report Prepared for MACPAC (2020); University of Minnesota, Research and Training Center (2020)*)

Parity for ICFs will help families and individuals with intellectual and developmental disabilities and the ICF/IID direct care workforce with a relatively small budgetary impact.

- Currently, for every $8 of Medicaid funds spent on Home and Community-Based Services (HCBS), one dollar of Medicaid funds is spent on ICF/IID.

- The American Rescue Plan had a 10-percentage point federal Medicaid match *only* for HCBS.

- Money Follows the Person (MFP) is likely to be permanently authorized in reconciliation. This will feed the mounting pressure on states to halt access to ICF/IID, close and downsize ICF programs to satisfy MFP goals to raise spending on HCBS and decrease spending for institutional programs. This negates the choice of Medicaid beneficiaries and their families to their preferred form of health care.

- Another 10-percentage point increase in the federal Medicaid match *only for* HCBS (as is proposed for reconciliation) will greatly magnify the funding disparity and state budgetary incentives.

- Increasing the HCBS federal match is expected to improve wages of the direct care workforce, and this is critically important. However, HCBS and ICFs face the very same direct care workforce crisis. Like HCBS, ICFs are struggling to attract or retain sufficient quality direct care workers necessary to meet the needs of the men and women they serve. Like HSBS, ICFs are facing 50% turnover rates, a problem exacerbated for both by the pandemic. So, it would be unfair to address this workforce crisis only for HCBS. It also would be unwise, creating an even greater crisis for ICFs by giving HCBS a competitive advantage for critical direct care workers. Anyone interested in a direct care job would naturally be attracted to HCBS due to the higher pay, better benefits and training that an increased Medicaid funding would allow.

- The combined uneven fiscal incentives between HCBS and ICFs will drive state policy and budgetary decisions to the detriment of those families and individuals, particularly those with severe forms of intellectual and developmental disabilities and medical conditions, who choose to access ICF/IID settings that meet their needs.

- Given that one size does not fit all and the existing disparity in how funds are spent, congressional Medicaid fiscal policy should not put the thumb on the scale so heavily for HCBS that it makes HCBS the only choice for families with individuals with severe and profound intellectual disabilities and medical conditions. Congress should support the full range of settings and care, even though a very small number of individuals prefer and choose ICF/IID.

BACKGROUND ON INTERMEDIATE CARE FACILITIES

The number of people in ICF/IID settings has declined precipitously over the years as those for whom HCBS is appropriate have transferred out of ICF/IID. The current population of ICF/IID residents represent roughly 6% of those with IID that receive Medicaid-provided long-term supports and services. This group of individuals is older, has severe or profound impairments and is medically fragile. (*University of Minnesota, Research and Training Center (2020)* For them ICF/IID is the best and least restrictive setting of care.

The Olmstead decision takes pains to point out that an ICF may indeed be the least restrictive setting for an individual, as determined on a case-by-case basis.

"'Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing that, on a case-by-case basis, that setting may be in an institution.'" Olmstead v. L.C., 527 U.S. 581, 605 (1999) (quoting Brief of VOR et al., as Amici Curiae at 11). See also, "We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. ... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." Id. at 601-602.

Congressional Medicaid fiscal policy incentivizing HCBS while disincentivizing access to ICF/IID services will lead to the tipping point of collapse of staffing and quality services. A modicum of parity is needed, specifically increasing the federal match for ICF commensurate to HCBS. This will help the direct care workforce that serves IID whether in HCBS or ICF/IID.