BACKGROUND

Long Term Supports and Services: The federal/state Medicaid program is the major – often only – source of funding for long term supports and services (LTSS) that many people with intellectual and developmental disabilities (IDD) rely on to live in the community. This effective and cost-efficient program is critical to people with IDD, making it possible for them to live and work in their communities with family and friends.

Home and Community-Based Services: The term LTSS includes both facility-based services and home and community-based services (HCBS). HCBS includes assistance with living independently, getting around the community, employment, and other activities of daily living. Unfortunately, many states have long wait lists for Medicaid HCBS. People with IDD wait an average of over five years to access these essential services. Many states are also facing workforce crises because Medicaid does not pay direct care workers a living wage.

ISSUES

Protect and Expand Medicaid: Medicaid provides vital health care and HCBS for people with IDD. The current program covers over 11 million people with disabilities under the age of 65. Medicaid services are already underfunded in many states. Congress must keep Medicaid cuts out of any upcoming deal to fund the government or address the debt ceiling. Additional investments are needed in Medicaid, not cuts.

The HCBS Access Act (S. 762/H.R. 1493): The COVID-19 pandemic has shown the public health danger of large congregate settings, but because HCBS services are optional in Medicaid, many people with disabilities cannot access them and are on waiting lists. Federal law requires states to provide services in institutions, such as nursing homes, but makes HCBS optional. This is why Medicaid has an institutional bias. The institutional bias also means that people may not be able to leave their state, because

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they might not be able to access the right services or would have to go onto a waiting list if they moved to another state. The HCBS Access Act would make HCBS services mandatory and reverse this institutional bias.

**The Better Care Better Jobs Act (S. 100/H.R. 547):** It is long past time to invest in HCBS to address waiting lists and raise wages for direct care workers. The Better Care Better Jobs Act would invest over $300 billion in the HCBS system, reducing waiting lists and increasing wages for direct care workers. Significant investments are needed to preserve and expand access to services and address the crisis in the workforce. The workforce crisis is worse than ever. Low wages for direct care workers have led to worker shortages and increased turnover. People cannot access supports due to these shortages. In many states, insufficient state Medicaid reimbursement rates do not allow an adequate response to these urgent needs, making a federal response even more critical.

**Adequate Housing:** Congress must adequately fund affordable, accessible, and integrated housing to ensure that low-income people with disabilities can remain in their communities or transition from institutional settings. One important program is the Mainstream voucher program. Congress should provide $667 million for this program in FY 2024. We also recommend increasing access to Mainstream vouchers to people with disabilities who are institutionalized or at risk of institutionalization. Another important program is HUD Section 811 Project Rental Assistance (PRA). We recommend at least $400 million in new funding annually.

**WHAT SHOULD CONGRESS DO?**

- Oppose Medicaid cuts.
- Pass the Better Care Better Jobs Act (S. 100/H.R. 547) and the HCBS Access Act (S. 762/H.R. 1493).
- Provide funding to address the direct care worker crisis.
- Increase funding for affordable, accessible, and integrated public housing.