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Dear State Directors of Developmental Disabilities Services,

VOR – A Voice of Reason, is a national non-profit organization founded over 40 years ago to advocate for high quality care and human rights for people with intellectual and developmental disabilities and autism (ID/A). Our membership consists of families whose sons, daughters, sisters, and brothers are those individuals with the highest medical acuity needs. Realistically speaking, many are fully grown teenagers or adults who have the mental capabilities of infants or toddlers and who rely almost entirely on services provided through Medicaid programs.

We are very concerned about Congress' intention to alter Medicaid funding. Whether through cuts to the Federal Medical Assistance Percentage (FMAP) that states receive from the federal government or by changing the structure of the program to instituting block grants or per capita cuts, each of these proposals has the potential to drastically reduce life sustaining services to our family members with ID/A.

We appreciate the good work and the dedication of State Directors of DD Services. We understand how very difficult your job must be - balancing budgets against available resources, supporting providers, working with managed care companies, attending to waiting lists, and trying to find the most appropriate services for each of our loved ones with ID/A. You are the people who are uncredited when you get things right, and often blamed when things go wrong. You are the ones who make the difficult decisions that affect so many lives.

The proposed changes to the Medicaid disbursements will take the funding for services for our loved ones out of the federal budget and pass it on to already tight state budgets. It puts the responsibility for caring for the people of your state on the shoulders of state governors, and ultimately, of you, as Administrators of DD Services.

Changes to the way Medicaid is structured will challenge all providers who care for our medically complex family members. These providers are already struggling to maintain services and allocate staff for these beneficiaries with current rates of reimbursement that are below cost in most states. Cuts in funding will cause many of providers to go out of business – leading to a cascading of job losses. Cuts will affect business owners and their administrative staff, as well as therapists and direct service professionals. These cuts will not discriminate based on where these beneficiaries live: at home with caregivers, a Home and Community Based Setting (HCBS) or an Intermediate Care Facility (ICF). In addition, many *more* families will be forced to become the primary caregivers and set aside their own careers. We should be creating more jobs to meet the current needs, not cutting them and further reducing tax revenues.

As you know, the federal government currently covers 68.9% of Medicaid costs in the U.S., with states paying the balance. In seven states, the federal government pays over 80% of the funding for Medicaid programs.¹ Cuts in federal Medicaid funding will negatively impact your state budgets. Projections from the Congressional Budget Office and the Center for Budget and Policy Priorities, the burden on your

state's budget will continue to increase annually.² This will impact state services for non-disabled people. As well, thousands of your constituents will become uninsured, straining other community health, law-enforcement, and social services. According to Georgetown University's McCourt School of Public Policy, federal Medicaid cuts will be especially harmful to small towns and rural communities.^{3 4} Finally, states' credit ratings will also be at risk, affecting their ability to borrow for other projects, like building roads, bridges, or schools.⁵

With an increase in uninsured numbers and the ID/A community's care reduced, delayed or denied, hospitals will be unable to provide sufficient services. Emergency rooms are already overburdened with mental and behavioral health patients, and any of the funding changes would crumble the system.

Medicaid is a complex program that serves a varied population with few resources. All participants, including state governments, work to control costs better than other health care systems or private plans. We ask you to protect our loved ones, to protect the jobs and livelihood of health care professionals and provider agencies, and to protect your own state's budgets by joining with us and voicing your objection to these drastic federal cuts to Medicaid.

We encourage you to speak with your Governor, and urge them to speak up to your Senators and Members of the House of Representatives to oppose any cuts to Medicaid in the 119th Congress.

VOR would appreciate discussing with you the best approaches to both protect the individuals and families we represent and prevent states from being held accountable - financially and publicly - for federal level decisions that do not reflect or consider the realities of state needs, provider needs, nor patient needs.

As you engage on this issue, please reach out to our Executive Director Hugo Dwyer at hdwyervor@gmail.com to arrange a time to meet and work together to ensure your state's Medicaid program is as strong as possible.

¹ <https://www.kff.org/medicaid/state-indicator/federal-state-share-of-spending/?currenttimeframe=0&sortmodel=%7B%22colId%22:%22location%22,%22sort%22:%22asc%22%7D>

² <https://www.cbpp.org/research/health/medicaid-per-capita-cap-would-harm-millions-of-people-by-forcing-deep-cuts-and>

³ <https://ccf.georgetown.edu/2025/01/15/cuts-to-medicaid-will-shift-costs-to-families-providers-and-will-be-especially-harmful-to-rural-communities/>

⁴ <https://ccf.georgetown.edu/2025/01/15/medicaids-role-in-small-towns-and-rural-areas/>

⁵ <https://ccf.georgetown.edu/2025/01/22/cutting-federal-medicaid-payments-to-states-bad-news-for-their-credit-ratings/>