To: DDRSwaivernoticecomment@fssa.IN.gov

To the Division of Disability and Rehabilitative Services,

In December 2023, Indiana's Medicaid office uncovered an accounting error of roughly \$1 billion. We are aware that Family and Social Services Administration (FSSA) has announced, as part of its strategies to address this shortfall, an intention to change attendant care pay policies for legally responsible individuals. We see attendant care pay as beneficial in multiple ways; it allows individuals in need of care to receive it from those who know them best, while also keeping households financially stable and reducing the burden on medical staff arising from Indiana's nursing and health aide shortage. This program is also an essential part of Indiana's commitment to family values, and to supporting individuals' freedom to live with their loved ones.

The impact of shifting families out of this program would be especially harmful to families who are at or near the poverty level. The <u>Indiana Self-Sufficiency Standard Calculator</u>, which provides an estimated basic needs budget by family type and county, suggests that a wage of \$10-15 an hour *may* provide adequate income to be self-sufficient - at least for some families. In the new proposed policy, families might only receive \$30 to \$80 a day, which is certainly not enough to replace a full-time job and keep families housed, fed, and safe.

As of 2021, 1 in 3 adults in Indiana (1,457,378) has a disability, and 16.5% of Indiana's population is elderly (CDC, 2021; U.S. Census, 2022). Additionally, 8% of all Hoosiers have a disability that gives them "serious difficulty" in independently living, impacting everything from dressing to going to doctor's appointments (CDC, 2021). Hoosiers with disabilities also experience poverty at higher rates as a result of the high costs of care and the inaccessibility of workplaces or inability to work (Indiana Poverty Hub, 2022). This often leaves disabled and elderly Hoosiers reliant on family or other loved ones for caretaking and financial support.

Meanwhile, the average cost of care for at-home help (not even an at-home nurse) is roughly \$4,767 (hourly: \$27/hour) in Indiana. This is roughly three times more expensive than the current payment scheme for family members to care for one another. This also assumes that home health workers are available–many Hoosiers report not being able to home healthcare and live in healthcare deserts (<u>America's Health Rankings</u>, 2022). Will there even be care available for these individuals?

When available, the care reimbursement from Medicaid for professional help is capped at \$30,276, which wouldn't be enough to even cover seven months, let alone a year. The alternatives - more expensive in-center care - would displace disabled children from their homes. Because parents of children with disabilities still have to attend doctor's appointments to learn how to care for their children, this would likely preclude them from being able to work jobs that require consistent schedules.

One Hoosier who will be affected by the proposal currently serves on our advisory council. Her experience speaks to the human impact of this proposed change:

"I am a foster parent in Dubois County. My foster (soon to be adopted) daughter is severely disabled due to Dandy Walker Syndrome and cerebral palsy. She is two years old and cannot move her legs much. She cannot stand nor walk (and probably never will). She eats only tube feedings every three hours. She relies on oxygen as well. She has been hospitalized repeatedly due to the severity of her conditions. She has to attend speech, occupational, and physical therapy 5 times per week in addition to numerous doctor appointments (she has 12 specialists).

[As a result of the FSSA program] my husband was able to start staying home with her and [we got] some of the lost income back.

This ability to have a parent stay home to care for her is going to be especially important when our foster daughter starts school in one year and needs someone with her for those school hours plus therapy and appointments.

Medicaid is proposing budget cuts that forbid family members from being the caregivers for these kids. [But] a hired unskilled caregiver cannot give her tube feedings, give her any medications, or perform several of her daily needs because they are not considered to be within their scope of practice. Parents are allowed to do this because they are trained during doctor appointments with their child. So, a parent would still need to be with their disabled child at all times regardless of if we had a hired unrelated caregiver."

We recognize that the shortfall needs to be addressed, but there are alternatives. According to State Auditor Tera Klutz, quoted in the <u>Capitol Chronicle</u>: "Indiana's historic \$6.1 billion reserve balance gives legislators the flexibility to look at the statewide funding model as well as provide Indiana residents with assurances that Indiana can continue to provide essential services as our country confronts an uncertain economic future." Given the strong economy of the state of Indiana and the 2023-2024 surplus of \$2,926,200,000 that the state began with, this program can be saved without making these cuts.

Examining the state budget further: Indiana spent an additional \$1 billion in surplus refunds to taxpayers, \$2.5 billion to help the Indiana state pension, \$3 billion in one-time projects, and \$1 billion on overspending beyond the Medicaid budget in 2023. This comes out to 7.5 billion over the standard/expected Indiana budget. However, the surplus in reserves only decreased by approximately 3.2 billion. This demonstrates that without the additional spending to purposely decrease the surplus, Indiana revenue is still approximately \$4.3 billion dollars higher than our planned budget each year. On this basis, we could increase the Medicaid budget (by as much as \$1 billion) while still having enough left over (\$3.3 billion) to increase the surplus fund every year. We also have a relatively low corporate and personal income tax rate compared to the rest of America–even a fractional increase in that could provide the money needed to fill this gap if we didn't draw from our significant surplus.

It is absolutely critical that we continue to support those who are caring for our most vulnerable – and do so at a level that keeps Hoosiers from falling into poverty or forgoing basic needs. The proposition that hourly wages for hard caretaking labor already at a fraction of the price of paying for nurses should be replaced by an even-lower daily wage is not one that will allow Hoosiers to thrive. More families will be forced to choose between caretaking and eating, between putting children with disabilities in care homes and paying rent, undermining the family values that we seek to foster as Hoosiers.

For these reasons, we urge you to find other strategies to address budgetary concerns.

Erin Macey & Zia Saylor

Indiana Community Action Poverty Institute