The RESOURCE CENTER FOR ACCESSIBLE LIVING, INC. Opening the Doors of Opportunity

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The Resource Center for Accessible Living, Inc. (RCAL) is the Independent Living Center (ILC) for Ulster County since our founding in 1983. RCAL provides advocacy, information and support to assist individuals with disabilities in Ulster County of all ages to live independently in the community. RCAL operates in accordance with the conviction that people with disabilities can and should make their own choices and decisions and take control of all aspects of daily living including education, employment, housing, health care and recreation.

Medicaid Global Cap

RCAL is deeply concerned about forced austerity for people with disabilities and seniors. The continued implementation of an artificial spending cap disproportionately affects the individuals we work with that depend on capped programs. The proposed inclusion of the Nursing Home Transition and Diversion program will impact the ability of people to avoid more costly institutional settings by imposing this artificial cap. Medicaid redesign should be focused on supporting these innovative programs to eliminate the need for higher cost services.

Consumer Directed Care

We were extremely upset to learn about several proposed changes to the Consumer Directed Personal Assistance Program (CDPA). This program provides the option of people or their guardians to self-directed personal assistance services through a Fiscal Intermediary (FI). Our ILC does not offer CDPA services as a FI, but we understand the important role these services play for the individuals that live in our community. These vital services allow people to live independently and escape barriers that have previously existed for people with disabilities.

Self-directed care is philosophically aligned with the Independent Living Movement which states that people with disabilities know what best serves their need. New York was the first in the nation to offer the CDPA program and should continue to do so. The state should show higher regard for a program that has been successful for decades in helping people lead independent lives while saving costs associated with improper levels of care or institutionalization. We share the concerns of many others that proposals currently on the table may lead to a federally required redesign of the program that is harmful and may end the program entirely if not approved by

CMS. We could see the state fall decades behind in delivering services to people with disabilities.

Several changes have already been recently implemented in combating fraud and abuse that are projected by the Department of Health to save the state millions of dollars. The federal government is requiring Electronic Visit Verification to track when and where CDPA services are used. The State is implementing new requirements on Fiscal Intermediaries to be approved providers. With several additional changes all at the same time it seems as though an ill-conceived shotgun approach is being taken to create possibly problematic fixes for a program which is working extremely well for many people.

We would ask that leaders in delivering CDPA services and the community of CDPA participants be consulted in developing program improvements instead of shortsighted fixes.

Home Care Crisis

Even when individuals are approved for assistance services in the community it is increasingly difficult for individuals to find caregivers. The situation has remained a crisis for years now. The CDPA program has over the years expanded caregivers to include people with a relationship to those needing services, but with certain limitations, and this was done to fill needs. Caregivers that are know to an individual outside of caregiving are more likely to work for the lower wages that do not provide a living wage. Traditional care service providers also continue to have trouble attracting employees as they compete with other industries and employers.

Home care workers are in desperate need of wages that reflect the costs of living and importance of the work. The wages for workers are low enough that there are consistent shortages for people in Ulster County willing to do the work. This can lead to serious impacts on families where someone may have to drop out of the workforce and take time off work to fill gaps. Individuals are unable to even receive community services without these emergency fall back workers that are unpaid and overburdened by consistent workforce shortages.

Provider Prevails

All medications can vary to some degree and will occasionally cause disaster in a person's life when costs savings are put before a serious medical need. We have handled a specific case where an individual was working and functioning independently with a mental health condition managed through a physician prescribed treatment plan. When one of these medications was switched to something different it created havoc in this individual's life. They became unable to work for an extended period and had to receive inpatient treatment. It was a months long upheaval in this individual's life that could have been avoided if the original treatment plan was consistently followed.

We strongly urge that physicians remain in control of life altering decisions on pharmaceutical treatment plans. They have the knowledge of a individual's needs and can work with them to prevent a crisis.

Spousal Refusal

Our state should continue to stand up to outdated assessments of need that place our seniors and people with disabilities in precarious poverty level living situations. Spousal refusal in New York is a long standing commitment we have so far kept to save the neediest in our communities the difficult choices of poverty or their loved one's care. When so much is said about upholding progressive values in New York we must stand true to our existing commitments. The proposal to end spousal refusal is a retreat from what is the right thing to do. We urge that our allies in the Senate and Assembly will stand up again to what is wrong.

Respectfully,

Alex Thompson, J.D.

Systems Advocate

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