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For the Working Disabled not covered by IHSS & AT; IHSS Sustainability and its Future: For the Listening Sessions of 1/6/2020 and 1/10/2020

Good afternoon esteemed members of this State panel on the Master plan for the Aging and Disabled with regard to Homecare!

My name is Lillibeth Navarro and I live with the severe consequences of Polio. I use a motorized wheelchair, and a ventilator at night to rest my weak lung muscles. I work full time as Executive Director of CALIF, the Independent Living Center for Central and South Los Angeles.

Before I took the step into full time work many years ago, I was on SSI and MediCal. I had subsidized housing with total accessibility and I had assistance with personal care and errands through a once simple and efficient IHSS program. I thought I was set for life but I knew that somehow, I needed to work and use my God-given talents to serve my life-purpose. As a consequence of that decision, I literally lost all of my secure set ups with MediCal, SSI and IHSS.

My work provided me with health insurance yes but with such ridiculous limitations that seemed to negate everything that defined me as a disabled person! My HMO rejected my application for a new motorized wheelchair as a medical necessity and would only accept a manual wheelchair as a Durable Medi-Cal Equipment. Never mind that the motorized chair enhanced my mobility 90 x more than a manual chair and that with it, I could do a lot more things and cover more territory on my own. When they finally accepted the existence of my motorized wheelchair, they made me wait 11 years before agreeing to replace it with an exorbitant co-pay. With my HMO, there was no access to a rehabilitation hospital with a special expertise on polio, no seating clinic, no real disability appropriate-therapy without costing too much money outside my HMO. But the worst of it all was the loss of my IHSS worker.

Just when I thought I could have someone making breakfast before I left for work, that someone was to help fix up the apartment for when I return, that I can get a little body massage for my poor and aching parts at the end of the day. Oh no, there was none of that. Instead I had to do everything without help, pushing myself to the max, with very little time to rest. If I wanted help and respite, I had to pay for it myself for at least twice the usual rate people pay for a caregiver. When my expenses all added up compared to when I wasn't working, I was either always short or just breaking even!

For the working disabled who had MediCal and IHSS before but lost both through employment, may I please suggest the following:

1.) Continue to provide a modified kind of Medi-Cal that covers the following:

a. Assistive Technology, i.e., Durable Medical Equipment like wheelchairs that enhance the abilities of the disabled worker and recipient so that instead of being punished for working, people with disabilities feel rewarded for their initiative. Assistive Technology (and DME in this case), even enhances the productivity of the disabled worker and makes working truly rewarding.

b. This modified Medical card should also cover for the repairs and maintenance of the DME.

c. This modified Medical card should also provide access to a rehabilitation hospital, a seating clinic, special physical therapy. Often these things are not provided by regular HMOs that do not have full service rehabilitation centers. In these cases, working people with disabilities should then have access to these facilities apart from their HMOs either through waivers or through special MOUs between hospitals.

2.) Provide a thoughtful transition process for IHSS for people with disabilities weaning off the regular IHSS program of home care to an HMO-provided service or whichever mode of home care they prefer. Abruptly cutting a severely disabled person using the regular IHSS is cruel and disorienting and can be the biggest disincentive to working. The process should include:

a. Reasonable needs assessments with realistic timelines for a transition process.

b. Providing options for non-IHSS home care: This should include a careful review of the IHSS task list and identify the things that the HMO already provides for its members and/or the tasks that members with disabilities should ask for and/or require the HMO to provide under the ADA and health care rights.

On the topic of the sustainability and the future of IHSS, make sure that the working disabled are an integral part of it. Why so and how?
1.) We know that because of institutional discrimination by the insurance industry, people with disabilities are not eligible to purchase life insurance and Long Term Care services. To overcome that institutional bias, I suggest that a program be created that allows people with disabilities, while still working, to pay into a future IHSS fund similar to the mandatory unemployment insurance that kicks in when the disabled worker retires. This assures them that in their cessation of work, they can fall back on IHSS for their continued personal care.
2.) Design this new fund as connected to the Working Disabled program of Social Security, to make sure it is properly implemented and tracked.
3.) Guard this retirement IHSS fund so it is protected from being co-mingled with other funds and programs and allow it to grow to assure its enhancement and sustainability.
4.) Provide a special IHSS program for the Working Disabled with HMO services. Review the tasks potentially and already covered by the HMO which IHSS should no longer cover and make sure that the task lists are clearly defined so that IHSS can claim some budget savings.

Respectfully written and submitted by:
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