

CALIFORNIANS FOR DISABILITY RIGHTS, INC

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February 3, 2015

Anastasia Dodson,
California Department of Health Care Services
Via Email: WaiverRenewal@dhcs.ca.gov

**RE: Section 1115 Medicaid Waiver Renewal–Workforce Development
In-Home Supportive Services**

Dear Ms. Dodson:

Cc: Statewide Disability & Senior Advocates & Concerned Citizens

Tonight the CDR Legislative Committee voted to sign on to the excellent letter I helped write for the IHSS Consumers Union (which was founded by CDR) and the CICA/CAPA letter regarding a training component added to the 1115 Waiver renewal. I will not repeat the letters but will emphasize the most important points that were brought up. CDR is a strong supporter of disability rights and disability justice as well as the Independent Living Movement; IHSS is a very important component of this.

I'm sure you will see a chorus of unanimity that a "voluntary" training policy like this could be a final blow to the Independent Provider Mode of Consumer-Directed In Home Supportive Services. One Executive Director of an independent living center put it this way: "This will put people right back into nursing homes. People get into this work, often for helping family members, friends, or people they know. If you make it this hard for people, they simply won't be able to afford to help anymore and this will drastically shrink the pool of available providers."

The consumers' Union and everyone associated with IHSS believes that IHSS is a jewel of public policy when it is permitted to operate simply and elegantly as it has for decades. In fact, other people in other states envy our model. It is the closest possible representation of an implementation of the spirit of the Olmsted Supreme Court decision and the Disability Civil Rights Movement. One of the things we don't want is MEDICALIZATION of the program and we certainly don't want nurses running the training!

Formal training undermines the key role that consumers have in training their IHSS provider and directing their own care. As the IHSS Consumers Union points out when such a burdensome, ill-conceived policy is put together without a clear understanding of the destructive potential it could have for the IHSS provider pool, it is a disaster. IHSS has helped make it possible for people with disabilities and seniors to live productive lives in the community without being forced into institutions. The program was designed and based on this independent living concept and is one of the reasons why IHSS has been so successful in reducing institutionalization: consumers are the most informed about what help they need.

If empowerment of consumers is the goal why not empower them rather than their IHSS providers? IHSS and the independent living movement were born and thrived as a direct response to the long history of others speaking for and about people with disabilities, so the idea that public funds would be used to return to that model is **disgusting**. This training concept ignores the cornerstone and foundation of IHSS: Including the fact that: 1) the consumer is the employer, 2) half or more of the providers are never going to work for anybody else, 3) there is no evidence that random training leads to better outcomes for consumers, and 4) not only do IHSS workers not have a clear obligation to coordinate care, they have **no right** to coordinate care. YOU SHOULD ALWAYS INCLUDE. It would be much better to raise the wages of the workers than spend that money on un-necessary training!

CDR A FORCE FOR CHANGE

One of the core mandates of Public Authorities is to provide access to training to both IHSS consumers and providers. Public authority training programs are set up in cooperation with local education entities and are providing quality training to providers and recipients. Do not legislate training, leave the training to the Public Authorities, they are much closer to the consumers and providers and in tune with their needs.

We note that the legislature mandated CDSS to develop a “voluntary” IHSS provider training curriculum that addresses issues of consistency, accountability, and increased quality of care for IHSS recipients, no later than January 1, 2014. We are happy that the workgroup was composed of representatives from CDSS; DHCS; counties; Public Authorities; IHSS consumers and providers; advocates; labor unions; and California State University, Sacramento, College of Continuing Education. Why didn't you use this work group to work on the 1115 Workforce Development? We found out that the stakeholder process primarily included licensed health practitioners AND EXCLUDED THE VERY RECIPIENTS OF THE SERVICE THAT IS BEING CONSIDERED. Haven't you heard “**NOTHING ABOUT US WITHOUT US!**”? No policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy. We believe that the CONSUMERS AND WORKERS in the IHSS community and disability rights advocates, should have been included in any discussion about including IHSS training in the 1115 waiver!

In case you have not heard, in 2011, Washington state voters approved a Mandatory Training Initiative. Subsequent studies have revealed that 59% of IHSS providers did not complete the process and did not obtain a home care aide certificate. This means that many IHSS consumers were either institutionalized or went without adequate care. We are very concerned that any mandate for IHSS provider training would have similar results in California; many consumers would be disconnected from their provider-of-choice and may be forced into institutions—that is totally against the philosophy of Independent Living!

People with disabilities and senior citizens or a representative sample of them, such as CDR, IHSS Consumers Union, CICA, CAPA, DRC, AARP, UCP, etc. should always be included in all discussions of matters having to do with them. Given the rapidly approaching deadline for DHCS to submit the 1115 waiver request to CMS, we recommend that **DHCS exclude IHSS training from the final waiver package**. We would be more than happy to assist you with finding people to help you in your work groups for the waiver. Please keep us informed of your actions. Thank you.

Sincerely,

SUSAN CHANDLER

President
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Cc: Statewide Disability & Senior Advocates & Concerned Citizens
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