

*Dear Fellow IHSS Consumers and Our Supporters,*

*There are big movements afoot for re-organizing the IHSS program. Read about it at [Duals Integration Demonstration](http://www.dhcs.ca.gov/provgovpart/Pages/DualIntegrationDemonstration.aspx) (<http://www.dhcs.ca.gov/provgovpart/Pages/DualIntegrationDemonstration.aspx>). Several organizations in the state: unions of care providers, Public Authorities, County Welfare Directors, health insurance companies, and other organizations have all given comment. Current IHSS consumers, however, those most affected by these changes, were seldom, if ever, consulted in many of the proposals put forth.*

*The formation of the IHSS consumers Union is the answer to a long wished for organization that speaks and advocates for our needs. Current IHSS Consumers' lives are radically affected by changes to the IHSS Program and need to have a say in the program. In response to some of the more difficult points made in some of the proposals, we have put together this list of demands that represent our views on our rights to determine our lives and hard won civil rights. We have also added demands that have always been missing from a true continuum of care.*

*We strongly oppose passive enrollment into any program that would deprive us of our individual providers, be they family members or the providers we have chosen from the community. This is viewed by the IHSS Consumers Union as a bad faith effort to trick us out of our genuine choice of how we receive our most intimate personal choices in in-home supportive services. Many of our people have difficulty responding to mail in time, which is especially egregious because the state no longer allows our providers to open our mail or read it to those who are visually impaired. We view this as a hostile attempt to trick us out of our true choice.*

*The following demands were put together to express what we cherish as our rights to control our own lives. If you agree, please sign on and join us as a Current IHSS Consumer Member (voting) or Supporting Member (nonvoting) whose support and input we value!*

*Nancy Becker Kennedy, Susan Chandler, Bertha Pool and Ben Rockwell and most importantly You!*

*Instructions on how to join at the bottom.*

# **NOTHING ABOUT US WITHOUT US!!!**

## **Alternate Formats Available On Request**

### **IHSS Consumers Union**

The In-Home Supportive Services (IHSS) program is a time-proven, cost-effective, exemplary model of person-centered care. In order to live independently, everyone would appreciate having consumer-directed, in-home care and assistance as an alternative to costly institutionalization. The California program has served as a beacon for all who age or acquire a disabling condition. The Disability Rights Movement has always been devoted to self-determination, therefore we demand:

- Creation of a carve-out for the Individual Provider (IP) mode for self-directing IHSS consumer for those who choose it.
- The right to choose the mode of delivery we most prefer.
- The right to use the IP mode, the most cost-efficient, stripped down method of attendant services because the money goes directly to the provider who delivers a service to the IHSS consumer. Some IHSS consumers prefer staying with the method they currently have, while others choose case management.
- Right to Active Enrollment: Passive enrollment into any program that would deprive us of our individual providers is viewed as a hostile attempt to trick us out of our true choice for the IP mode.
- That IHSS remain a person-centered social model rather than a medical model. Paramedical services and scheduling must conform to the IHSS Consumer's life: work, school, personal needs and preferences rather than any medical agency's shifts or procedures.
- Recognizing that there is a wide diversity in the capacities of IHSS consumers and that "One-Size-Does Not-Fit-All." Self-Directing IHSS Consumers who do not request case management must not be burdened with multiple visits by IHSS workers, case managers, nor required to have a care coordination team.

- IHSS Consumers retain their authority as the employer with the right to hire, fire, supervise, schedule, train and retain any Individual Providers (IPs) including family and community members and not limited to any person listed by a registry.
- Family member or significant other providers should not be made to give up portions of their attendant hours to strangers coming into their home.
- Self-directing IHSS consumers have the right to train their own providers in the personal-care methods they prefer. Stipends should be paid to incoming providers being trained by the consumer.
- Providers wanting additional training to improve their skills and employability may receive that training in educational settings, outside of the self-directing consumer's home.
- IHSS program paramedical services such as suppository, digital stimulation and catheter insertion, routine daily injections of prescribed medications (i.e. insulin), wound, ostomy, and catheter care will continue to be safely administered by a family member provider or attendant of the consumer's choice, as it has in the IHSS program for decades.
- No entities shall interfere in the independent relationship between the consumer and their provider.
- Profits / Administrative costs must never be at the expense of Consumer hours. Administering entities must have diligent oversight by both the State of CA & CMS (federal). Data collecting, tracking, outcomes stats and monitoring must be thorough, transparent & readily available to the public and cap of administrative costs must be upheld.
- As funds become available from reduced E. R., hospital, institutional care and profits, etc, these monies must be directly invested direct service rather than the administration and profits.

- Access to a universal standard of rehabilitation approved by National Institute on Disability and Rehabilitation, adequate to give people with newly disabling conditions proficiencies in Activities of Daily Living. Discharge planning must require discharge planners to secure a hospital trained family or community provider and connect the PWD with IHSS, California Community Transition program, Linkages, MSSPs or other ongoing community supports.
- People with newly disabling conditions who cannot return to inaccessible housing should be transferred to step-down, transitional housing until accessible housing can be acquired.
- Access to ancillary services to support community living, (i.e. Section 8 certificates and 24/7 emergency response services.)
- No care team, managed-care entity or individual provider has any standing or authority to monitor, inform on, or determine the self-directing IHSS consumer's decisions. IHSS consumers view this as patronizing and a flagrant violation of our self-determination and civil rights.
- Any health care provider must have access in the building they work to a hooyer lift to give persons with disabilities access to examination tables and fittings for durable medical equipment. Health care providers must assist persons with disabilities on to examination tables and disrobing as is required by the Americans with Disabilities Act ADA.
- Regardless of the mode of service delivery no Independent Provider attendant services can be disrupted. If any misunderstandings occur with enrollment, immediate care provider services must not be disrupted and must be permitted to continue seamlessly while other matters are resolved. To do otherwise is to endanger the person with disability or irreparably destabilize their independent living situation.
- Personal care or homemaker services offered by any entity must not be stopped after it is offered in the initial agreement.

Because the IP mode of IHSS requires nothing more than the actual cost of delivering services (i.e. money to the provider to care for the consumer), it is a particular blessing to governments in times of fiscal

difficulty. As the baby boomers age and need these services, its cost efficiency and utility will be undeniable. We, the undersigned current IHSS consumer members and our supporters of the IHSS Consumer's Union, believe there is no place like home for all citizens as they age or acquire a disabling condition. The above-mentioned demands are put forth in order to safeguard the dignity and self-determination of all persons who need In-Home Supportive Services.

*If you'd like to join the IHSS Consumer Union, email us at [IHSS.CONSUMERS.UNION.COM@GMAIL.COM](mailto:IHSS.CONSUMERS.UNION.COM@GMAIL.COM). Please include your name, whether you are a current IHSS consumer or a supporter, and your E-mail address or phone. If you have no email and say that you'd like to join to IHSS Consumers' Union.*