

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, the following protections are necessary:

- Creation of a carve-out for the Individual Provider (IP) mode for self-directing IHSS consumers 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.
- 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.
- 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.
- Recognizing 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.
- 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.
- 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.
- Regardless of the mode of service delivery no Independent Provider attendant services can be disrupted. **If any misunderstandings occur with enrollment, immediate attendant and medical 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.
- As funds become available from reduced E. R., hospital, institutional care and profits, etc, these monies must be directly invested in 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. Our brothers and sisters can get as little as two weeks of rehabilitation from serious injuries and be sent directly to skilled nursing facilities and **their active lives extinguished.** It is currently totally random whether you will get adequate rehabilitation. We demand a universal adequate standard of rehabilitation
- 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.
- Healthcare providers must have access to a Hoyer lift in the building where they work to give persons with disabilities access to examination tables and fittings for durable medical equipment. They must assist persons with disabilities on to examination tables and disrobing as is required the ADA.
- 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.

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. IHSS consumer members and our supporters of the IHSS Consumers Union believe there is no place like home for all citizens as they age or acquire a disabling condition.

<http://www.facebook.com/#!/groups/IHSS.ConsumersUnion/> ihss.consumers.union@gmail.com. For those without computers, our phone number is (213) 537-IHSS or (213) 537-4477.



NEW WORLD

For Persons with disAbilities

March 2012

Californians for Disability Rights, Inc.

Expo Edition

CDR ELECTS NEW OFFICERS

By Susan Chandler

At the October meeting of the CDR, Inc. the State Council, elected **Susan Chandler**, Los Osos, **President**. The other officers elected were: **Linda Hinchey**, Sacramento, **Vice President**; **Alisa Shuman**, San Diego, **Secretary**; **Buz Dreyer**, Woodland, **Treasurer**; and **Members at Large**: **Ruthee Goldkorn**, Riverside, **David Juare**, San Diego and **Ben Rockwell**, Long Beach. They will all serve two-year terms.

PARKING MOBILITY PROGRAM

CDR is working with Craig Spaulding of **PMP** in Austin Texas in implementing this program in CA cities and counties. Check out their web site at: www.parkingmobility.com and see how it works.

Essentially, after 4 hours of training, if you have a "Blackberry", "Android", or "Smart" phone, you can take 3 pictures of a disabled parking violation and then email it to the PMP group who then sends it to the jurisdiction who then issues a ticket to the violator.

The proceeds of the ticket are shared with the jurisdiction and PMP. PMP then gives 20% to the non-profit designated by the person who issues the ticket! So this is a great way for groups (CDR) to make some money for their organization. The idea for this came about because there are many places where the police and sheriff's offices don't have enough officers to ticket violators and they don't consider it a priority. Who better to report than these violations than those who need the spaces for maintaining their independence in the course of their daily lives?

It is a matter of Civil Rights for people with disAbilities who are trying to live their lives and function in society. As people go about their daily lives they come across these violations--they don't seek them out so this is a good way to sell the ideas to the cities and counties. We need CDR folks to get their cities & counties excited about this program. More later, you should get info at the LA EXPO.

PRESIDENT'S MESSAGE

PASSION!!! What are you passionate about? It seems to me that we have lost our **PASSION FOR OUR CIVIL RIGHTS!** I want to see CDR keep going but don't see a lot of passion from other members! Have you lost it? When I go out and find an access problem or a person with an access problem then my passion for civil rights comes right back! How about you? I get discouraged, but if we give up, **who will carry the torch for access?**

Do you want CDR to continue? As we are recovering from the shock of Laura's death, we have been trying to recover the database and getting the CDR "house" in order and sometimes I lose sight of my **PASSION!**

Fortunately, the membership renewals in 2011 came in at **92%** of the budget. We had some donations in honor of Laura, which brought the income to 92% of the budget. Our Expenses were 91% of budget. We always need new members and member renewals. We owe some on credit cards but the future is looking better and the **PMP** will make it even better!

Unfortunately, age and disability have caught up with a lot of us. David Juare was laid low and hospitalized, Linda Hinchey will be getting hip surgery in mid Feb. Ruthee is recovering from the office clean up and San Jose EXPO, as is Susan whose sore came back. But we are getting better and pushing forward!

The San Jose EXPO had 2500 adult visitors and I talked to a lot of them and got 2 members to renew and then enrolled 8 more new members. We had some interest in new chapters being formed and have a New Chapter packet we put on the web site.

Are you electronically connected? More and more these days' people are going to the internet to look up information and connect to their friends. People with disAbilities who have computers are especially savvy in using them to help them get better lives via the Internet. CDR members have the website and the Members Exchange. Many have created jobs for themselves and are earning their livings with them!

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**CDR's Mission - To Improve the
Quality of Life for All Persons with
any Disability Through Education and
Training - By Working to Remove
Barriers Through Advocacy and
Change in Public Policy.**

Originally organized in 1970 as CAPH
(the California Association of the
Physically Handicapped) --with five
members, CDR has grown to become an
effective and widely respected cross-
disability advocacy force.

IHSS CONSUMERS UNION FORMED TO KEEP IHSS OUT OF MANAGED CARE

Consumers have been rallying against Governor Brown's move to put IHSS into managed care. Nancy Becker Kennedy, Ben Rockwell and Susan Chandler have spent considerable time on this issue over the past month. A Facebook page with a list of protections has been established, the link is: <http://www.facebook.com/#!/groups/IHSSConsumersUnion/>. We also set up a petition <http://www.thepetitionsite.com/1/Keep-IHSS-out-of-Managed-Care/>. The first target was the Senate Health Committee for its hearing on Feb. 23rd and then the Assembly Committee on Aging and Long Term Care hearing on March 7th. We are now sending it to the whole CA legislature. Nancy Testified at the Senate hearing and Ben testified at the 5+ hour Assembly hearing. We would like you to write your legislator directly.

The following is the founding document written Feb. 5, 2012:

Dear Fellow IHSS Consumers and Our Supporters:

There are big movements afoot for re-organizing the IHSS program. Read about it at: <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 IHSS 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 also 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! **Join by sending an email with your name, indicate whether you are a Current IHSS Consumer, or 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. Email us at: ihss.consumers.union@gmail.com.** For those without computers, our phone number is (213) 537-IHSS or (213) 537-4477.

Nancy B. Kennedy, Ben Rockwell, Bertha Poole, and Susan Chandler

CDR FOUNDATION NEWS

Scholarship applications were received and reviewed and the results will be revealed on April 30th.

Kathleen Barajas, our Webmistress, has revised CDR's web site www.disabilityrights-cdr.org and the CDR Foundation can be accessed from that. It lists ways to donate to the foundation.

There are lots of ways to support the CDR Foundation & the CDRF Scholarship fund! CDRF is a 501(c) 3 tax-exempt organization.

Do you shop at **Ralph's**? Ralph's has a community fundraising program. Please go to their web site and sign up so that CDRF will earn MONEY: <http://www.ralphs.com/>. Participant registration for the new term begins on September 1, 2011; anyone registered MUST RE-REGISTER! CDRF's number is #82491.

[WWW.Goodsearch.com](http://www.Goodsearch.com) is also a way to support the foundation. You can use it as your home page and every time you log on CDRF earns something. There are others associated with it: Good Shop and Good Dining.

The Foundation is looking into various other fundraisers. If you have any ideas, please contact Kathleen Barajas, Foundation Chair, at kdbarajas@aol.com.

The Foundation is looking for more board members, especially people from the community who might be willing to help raise funds for CDRF. Please contact Kathleen at kdbarajas@aol.com.

President's Message

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I urge you to consider exploring the world of computers, face book, Google, Wikipedia, "smart" phones, Kindles, tablets, etc. and the "www" or wide, wide world! Hope to see you there!

We can now accept new memberships and renewals AND payments (as well as donations to the Foundation) via Pay Pal on CDR's web site!
Please visit: www.disabilityrights-cdr.org.

LA CHAPTER OF CDR FORMING! WOULD YOU LIKE TO HAVE CDR IN LA AGAIN?

Marvin Wasserman, of Hermosa Beach, is looking at gathering like-minded disAbility advocates in June. Please contact him at (719) 349-7317 or marvinwssrmn@aol.com, if you are interested.

ATTENTION LA & San Fernando Valley RESIDENTS W/disABILITIES

Have you had difficulties finding ACCESSIBLE PUBLIC HOUSING?

The Disability Legal Rights Legal Center (DLRC) and the David Geffen Law Firm are gathering information about the experiences of people who are looking or have looked for accessible public housing.

We are interested in speaking with you if:

1. You **COULD NOT FIND ANY ACCESSIBLE HOUSING.**
2. YOU WERE **TOLD there was NO ACCESSIBLE HOUSING.**
3. YOU WERE **PLACED on a WAITING LIST** for an Accessible Apartment.

We would like to speak to you.
Contact DLRC intake line at (213) 736-1334

And mention the public housing in Los Angeles

Or you can send an email to
Geffenlaw@aol.com