



NEW WORLD

For Persons with disAbilities

September 2019

Californians for DisAbility Rights, Inc.

Fall Edition

PRESIDENT'S MESSAGE

By Kathleen Barajas

I cannot believe that summer is already over, and Fall is upon us. I am sure that many of us do not like the extremely hot weather, only a fully air-conditioned home does the trick, which many of us are not fortunate to have. Although I have not gotten all the things done that I had hoped I would, it's been a busy summer nonetheless.

In June, I got appointed to LAX's Disability Access and Accommodation Advisory Committee. This committee had been on my radar a few years now; a good friend of mine mentioned that they were looking for new members, so I felt that was my cue. As I travel several times a year through LAX, mostly on my own, I encounter issues which I can bring to this committee to work on.

Summertime to me usually equates to going to concerts and baseball games, and if I am fortunate, a trip or two. This summer I was blessed to go with my family to Maui, and then with a dear friend on a cruise to Ensenada. As many of us know too well, traveling with a disability is never a dull moment; I have written an article related to travel later in this newsletter.

Going to concerts and baseball games/sporting events should be much simpler than traveling, and while it is, I have still encountered significant issues with each. Here in Los Angeles, a major concert venue is the Hollywood Bowl. I have gone to the Hollywood Bowl for many years, but have always gone in someone's car. A convenient service that the Hollywood Bowl provides is Park and Ride Shuttles from various locations around Los Angeles. Several years ago, I attempted to take the shuttle with a few family members. The website said that shuttles were wheelchair accessible, and that you could pay when you got to the Shuttle Lot (instead of paying ahead of time online). Because the lot we were using was not too popular, there was to be only one shuttle. When the shuttle arrived, it was a tour bus, with no wheelchair access. Luckily, we had our van in the parking lot, so we had no choice but to take that.

(Cont. on page 5)

THE WILLITS CASE

By Cynde Soto

Filed in 2010, this lawsuit alleges that the City of Los Angeles violated federal and state disability access laws by denying individuals with mobility disabilities access to sidewalks, intersections, crosswalks, streets, curbs, curb ramps, walkways, pedestrian rights of way, pedestrian under crossings, pedestrian overcrossings, or other pedestrian pathways or walks, controlled or maintained by the City in whole or in part.

CDR, along with other disability rights groups, are calling out City leadership and its failure to comply with the Willits' Sidewalk lawsuit settlement in 2015, which sets out a plan and \$1 billion investment to create and fix sidewalks, curb ramps, crosswalks, and pedestrian crossings, as their compliance obligations under the federal Americans with Disabilities Act (ADA).

We are calling on City leadership to provide:

- Clarity on how the City's street repair requests are prioritized and what role submissions by Angeleno's with disabilities play in the prioritization.
- A list of priority projects currently underway in LA.
- Explanation of the City's strategy on Willits settlement compliance and the use of its \$1 billion investment.
- Contact information of the compliance officer overseeing the Willits settlement.

For more information and answers to common questions about the lawsuit and the Settlement, see the Settlement Website at <http://www.LosAngelesADASettlement.org>. You may also call, write, or email Class Counsel with your questions at:

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**Californians for
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**United We Stand,
Disability Rights are Civil Rights**

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.

A MODEL HOME SAGA

By Susan Chandler

"It is a terrible fact, but you cannot ever rest. Fighting for your rights is a never-ending job", says HolLynn D'Lil!

I have always loved going to model homes and open houses to view homes. In 2001, Ed, my husband to be, and I lived in Sacramento and could find NO existing homes that were wheelchair accessible! So we looked in the surrounding communities that happened to have many new housing developments. We were lucky to find one in West Sacramento. Every one of the model homes had a NO STEP entrance, which was wonderful. We had our pick of all of them! The builder of the one we picked was very accommodating, and gave us changes we needed for my specific disability needs, thanks to a rule that CDR got the Department of Housing and Community Development (HCD) to adopt.

In 2006, we moved to Los Osos in San Luis Obispo County. We could not afford the houses in the city of SLO, nor were many accessible, however we were able to find a fairly reasonable accessible place in Los Osos (12 miles west) which we were able to modify to our liking.

In about 2012, there was a new housing development, Serra Meadows, that opened up in SLO that I decided to explore. When I arrived, the sales office was accessible, but when I asked about going to see the single-story model home, that was a different story! The sales person said that I could view a video of the interior of the house; I insisted that I get to see it in person! I had to go down the sidewalk (not the normal path of travel from the sales office), cross the street, go through a gate, then when I got to the model home, there was a 4.75" step - YIKES! The sales lady said that other people in wheelchairs had gotten "bumped up" into the doorway, but even though I was in my manual chair, I did not think that was a good idea, so I declined! I tried to pursue the matter, but did very little due to health problems and surgery.

This year, I noticed that there was a new huge housing development called Rhigetti Ranch! When I drove by, I could see steps, unfriendly sidewalks, and stairs between the model homes. When I stopped by a few weeks later and went into the sales office, again I was not able to get into the model home due to another big step (I didn't measure it). I went to my car to get my handy 3" ramp, but that was still not high enough. The saleswoman offered to go get some men to help me get in (this was in my 400 pound wheelchair, plus my 160 pounds); I declined her offer. We tried going through the garage of the next home, and through a sliding door of another one, but they all had this huge step! The model homes are all up on a hill. WHY? there is no chance of flooding there!

My questions about this issue are as follows:

- Why did all the model homes in the Sacramento area have zero steps, while the ones in SLO and probably other nearby areas have steps?
- What can be done to correct this?
- Is the answer to sue the city and county, in order to get them to change this egregious policy?
- Isn't it illegal for sellers of Model Homes to not provide wheelchair access to them?

I wrote a letter to the Mayor of San Luis Obispo and the County Board of Supervisors, but have not received a response so far. Here is part
(Cont. on page 5)

CDSS PROPOSED CHANGES IN REGULATIONS - SIMPLIFIED CRIMINAL RECORDS EXEMPTIONS

By Connie Arnold

How would you feel if you were sent a new worker referred by an agency, only to find out that they are a felon? Well, California's DSS Office of Regulations Development is working on changing regulations regarding simplified criminal records exemptions!

CDSS now wants to grant expedited and simplified exemptions to those with past criminal histories, so they can take on caregiver jobs for the most vulnerable in society. Unbelievable!

I am opposing this action for convicted persons, affording them the ability to take jobs as caregivers for those most vulnerable, seniors and persons with severe disabilities, served by the Home Health Registry and California Community Licensed (CCL) facilities. This is a backwards proposal.

This is CDSS' answer to resolve our provider crisis, however it places many vulnerable individuals at risk, including children who cannot fight back and may not be able to prevent abuse, neglect, or abandonment by these previously convicted criminals!

Granting exemptions to past convicted criminals to be care providers who work in a facility or provide home care or agency provided care is both unreasonable, unconscionable, and counter to what the state should be doing to solve the caregiver shortage and crisis in this state. The same population of persons with severe disabilities may be served by these agencies and the IHSS and IHO (Integrated Systems of Care) Waiver system and programs. In an adjacent state, we had a vulnerable adult impregnated, and past criminal acts is a history that can be repeated or shows a propensity to commit a crime. In fact, elder abuse is increasing as reported in the Los Angeles Times this year.

Nancy Smith, an IHSS provider in Santa Cruz, suggested to Marko Mijic, Deputy Director, California Health and Human Services Agency, that it would be a good idea to give this work opportunity to college students. They could earn college credits for internships, working in the field of caregiving as IHSS providers, who could fill open jobs with CCL facilities. Why not think outside the box, instead of embracing expedited and simplified criminal record exemptions for persons with past criminal records, to be the new

(Cont. on page 6)

TRAVELING WITH A DISABILITY IN HAWAII

By Kathleen Barajas

Traveling on vacation is always fun, but also never dull when you have a disability! I always know that my upcoming vacation will be full of new adventures, with some related to my disability and the level of accessibility I find where I am visiting.

On my flight to Maui, I warned my family about the delays that might occur while going through security at LAX. I had not taken a flight with my brother and sister-in-law, so this was to be a learning experience for them. I asked them to take my purse and bag when we got to security, this would free me from having to take care of them myself and would hopefully get me through security a bit faster. To my surprise, this terminal which I rarely go through, got me screened in record time! My family was still putting on their shoes and retrieving our bags, when I let them know that I was finished.

Over the summer, I purchased a foldable power wheelchair, so that is what I took on my vacation. I usually am forced to take a manual chair, but as I cannot push myself in it, I am at the mercy of others to take me where I want to go. The one thing I love about these types of new wheelchairs is that they can stay with you in the cabin of the plane. There is a closet onboard some label the "ADA closet", where mobility equipment can be stored. Some airlines use this closet for the crew's luggage, but they are supposed to make it available, if a passenger needs it for their equipment. On my flight, the crew already had luggage in it but obviously knew the requirements and allowed me to put my wheelchair in there instead.

I found accessibility on Maui to be very good! The Kahului Airport was fully accessible, it is a single-story structure. The trolley which took us from the airport to the car rental area was also fully accessible, it was fun to ride in a vehicle that one does not always have where they live. We stayed at the Royal Lahaina Resort, which I had stayed at another time, so I knew that the wheelchair accommodations were satisfactory. The hotel sits by the beach, I was able to get to wherever I wanted to go on the grounds easily. Although there are stairs going from the dining area out to the pool area and beach, the hotel does have an accessible exit nearby which gets you to the outside area. I had an ADA room, which had a large bathroom. The shower was a walk in, which had a foldaway bench. Because of my short stature, these type of benches rarely work for me; the hotel did have a stand-alone bath bench which they brought to my room promptly.

(Cont. on page 6)

ELECTRONIC VISIT VERIFICATION (EVV) UPDATE

For those who are wondering what is wrong with EVV, the following was sent out to advocates on September 14, 2019. For Medicaid-funded personal care services, including consumer-directed services, the requirement takes effect January 1, 2020.

NATIONAL COUNCIL ON INDEPENDENT LIVING (NCIL) - PRINCIPLES OF EVV

- EVV threatens decades of advocacy work that created a true Independent Living Model for people with disabilities who wish to live and work in our their communities. ***EVV has no place in Personal Care Services or Consumer-Directed Services***, or in waiver programs that offer CDS-like options. While some states refer to their programs by differing names, CDS programs provide the consumer with: ***choice of service provider; location of service (home or community); scheduling responsibilities; and consumer control. EVV in all forms erodes these rights*** and eliminates consumers' ability to direct care at their own volition.
- Stakeholder groups must include and empower people with disabilities, independent of providers, to be drivers and experts in ***the development of policies that uphold the freedoms, rights, dignity, privacy, and independence of people with disabilities***.
- The federal EVV mandate, was not created because of the need to eliminate fraud in Medicaid personal care services, is instead, a massive financial giveaway to technology vendors of EVV systems.
- ***Global Positioning Systems (GPS) and biometrics are a direct and excessive violation of the privacy and potential safety of individuals living with disabilities.*** Given the growing frequency and size of private data breaches, consumers are or will be required to tolerate additional intrusions and burdens under EVV, just to receive the life-sustaining care on which they rely to live independently and avoid institutionalization. Americans are guaranteed Constitutional protection from these types of privacy intrusions, and ***disabled Americans demand equal protection under the law.***
- ***GPS / biometrics have a chilling effect on the independent provider / personal care assistant***
(Cont. on page 7)

MASTER PLAN ON AGING

By Connie Arnold

Governor Newsom announced members appointments to the Master Plan on Aging on August 15; NONE of our disability contingent group who wanted to be appointed to address shortcomings of the IHSS and IHO Waiver system were appointed. The only appointees to the committee representing our community will be Catherine Blakemore, Executive Director, Disability Rights California (DRC) and Christina Mills, Executive Director, California Foundation of Independent Living Centers (CFILC).

While many of us see this as another discouragement and setback to addressing any real issues of significance in the dysfunctional IHSS and IHO Waiver system, do not be so upset to let it silence our voices. Although we may feel individually discouraged, do not waiver in our commitment to create the change we want to see. Governor Newsom's Executive Order initially stated "any policy recommendations should build on California's work supporting people with disabilities living independently and reflect the principle of "Nothing About Us, Without Us". We MUST let our voices be LOUD and CLEAR that WE WILL NOT BE FORGOTTEN IN POLICY CHANGES AND DIRECTION needed for home and community-based services; our current long-term supportive services are not addressing our needs, concerns, nor our issues. The system is failing those of us with severe disabilities and impairments with the low wages to providers across the state, those on IHSS Advance Pay, and those on IHO Waivers or the waiting list some claim doesn't exist while others indicate a two year wait period for eligibility. Other models for services exist, consolidation under a new umbrella agency may be needed.

I am looking forward to receiving your feedback and ideas as to what you think CAN FIX THE IHSS SYSTEM! Most importantly, keep the faith, never give up, and keep on advocating through the Master Plan on Aging committees, teleconference calls, letters, emails, and even protests. Our voices MUST AND WILL BE HEARD!

- Secretary Gahly's press release regarding the appointment of the Master Plan for Aging advisory committee: <https://www.chhs.ca.gov/blog/2019/08/15/california-health-and-human-services-secretary-dr-mark-gahly-makes-appointments-to-master-plan-for-aging-stakeholder-advisory-committee/>

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PRESIDENT'S REPORT

(Cont. from page 1)

This summer, I decided it was time to try the shuttle again. This time, I got in contact with the Hollywood Bowl a few weeks before the concert, to let them know that I would need an accessible shuttle. We emailed a few times, and I was assured that one would be available, but I needed to purchase the tickets online ahead of time. When my family and I arrived at the lot, there were two tour busses there. Immediately I thought that the Hollywood Bowl has failed me, however as it turned out, one tour bus was wheelchair accessible. It had an older type lift, which I found archaic, but as long as it worked and was safe, I was fine with it.

The strange thing I found with Hollywood Bowl Shuttle's web was that although it does have a box to check if you require an accessible vehicle, they do not use that option as they should. When I was instructed on how to order my shuttle tickets, I was told not to check off that I needed an accessible vehicle. From our email interaction, they knew that I needed such a vehicle, but my question to them was how they would know that other individuals in other locations require an accessible vehicle. I stressed the fact that since they already have the option to signify the need for an accessible vehicle, they need to allow users to check off that option, so that the shuttle service will know where to send accessible vehicles. I was informed that they will consider my suggestions, and will get back to me if they decide to implement them.

Here in Los Angeles, Uber and Lyft are finally providing wheelchair-accessible vehicles! I have been using Uber since the beginning of the year, and started using Lyft maybe two months ago. So far, I am fairly pleased with the service. One rumor I heard is that Uber is only utilizing about half of their inventory of accessible vans; I have yet to find out the reason for this. I have encountered difficulties getting an accessible van late at night and at busy times of the day, thus there is definitely a need for more accessible vehicles.

Finally, the LAX Airport Committee is working on a survey to get out to travelers with disabilities who have used LAX in the past. As far as we know, this survey is the first of its kind in the country, if not the world, to be implemented; thus we as a committee are very passionate about this project. If you have traveled through LAX in the past few years and are interested in voicing your opinions, please email me at kdbarajas@icloud.com.

In advocacy always, Kathleen

MODEL HOME SAGA

(Cont. from page 2)

of the letter I wrote to the HCD, with their response following:

I thought it was mandated in the code and that a Model home is classified as a business. CDR, the new CAPH, helped write all the building codes in the 70's and 80's and it is coming up on the 30th year of the ADA! What is wrong with this picture? In this day and age in this community especially where people come here to retire, they need housing that can be easily converted to an accessible environment with ease and little cost! The major cost would be having to put in an elevator because there is no Universal Design for an easy conversion to use the ground floor for the accessible space needed.

"Hi Susan, I reached out to my colleagues at the Division of State Architect. Below is the answer I received regarding your question.

A sales office is regulated by the 2010 ADA Standards for Accessible Design as well as California Building Code, Chapter 11B however model homes are not.

The definition in Chapter 2 of the CBC defines a place of public accommodation as:

A facility operated by a private entity whose operations affect commerce and fall within at least one of the following categories:

5. A bakery, grocery store, clothing store, hardware store, shopping center, or **other sales or rental establishment**;

This definition is consistent with the definition in the 2010 ADAS.

That being said the model homes are not regulated by the 2010 ADAS or Chapter 11B. The following interpretation is provided by John Wodatch, ret. Chief, Disability Rights Section, US DOJ, in a US DOJ technical assistance letter that is still valid.

Are model homes places of public accommodation? Generally, no. A model home does not fall under one of the 12 categories of places of public accommodation. If, however, the sales office for a residential housing development were located in a model home, and they are used for the sales office it would be considered a place of public accommodation. Although model homes are not covered, the Department encourages developers to voluntarily provide at least a minimal level of access to model homes for potential homebuyers with disabilities. For example, a developer could provide

physical access (via ramp or lift) to the primary level of one of several model homes and make photographs of other levels within the home as well as of other models available to the customer.

Here is a related comment from a longtime CDR member, Hollyn D'Lil:

I just have to insert something here. Persons with disabilities do not have to justify why restaurants and other public accommodation should be accessible. It's the law. Both Federal and State restaurants can even get a tax credit, not a write-off, but a credit toward the taxes they owe when they remove barriers. See Tax Form 8826.

I guess I understand why so many people would like to persuade a restaurant owner to see them as people by arguing that some people with disabilities have money, but it really makes me sad. I hope you come to believe that you deserve the civil rights that so many fought for over the decades. I hope you will take action against the restaurant owner, if he does not remove his barriers. If more people are willing to go to court to demand that their civil rights are enforced, we will all benefit greatly.

Regarding housing: It is State and Federal law that the housing offices and model houses open to the public be accessible. Susan knows she can ask a lawyer to help her make the developer remove barriers in the public portions of the development. (Susan, writing HCD is a waste of time. You'll receive a polite letter in response and nothing will happen. But, damn, girl! You took action! For that, you deserve a big round of applause. Now, pick up the phone and call an attorney.)

Regarding the private houses, there have been many movements toward requiring Universal Design (UD). The City of Davis has adopted such a requirement. HCD is run by the California Building Owners and Managers Association, a private lobbying firm for developers, and CalBO, a professional organization of building officials who often act in the interest of the developers. HCD has always refused to do anything toward adopting UD at the state level, in spite of our years of efforts. You can, however, organize at the county and city levels and get UD required at the local levels; it's been done. Contact your local officials and start working on it; fill up a city council or supervisor's meeting with persons with disabilities. It is the only way we have ever gotten anything - by organizing and showing up.

And, yes, I've asked and actually gotten UD in a new development here in the tiny town of Graton. I was lucky, the developer is a good human being. I

have not done anything at the county level, though I spent decades working with HCD, and was able to get apartments and condos accessible with three or more units in a building.

It is a terrible fact, but you cannot ever rest. Fighting for your rights is a never-ending job. I know that right now many of you are fighting the horrible changes to IHSS reporting, and others are having their lives threatened by PG&E shutoffs. It's too much, but we cannot give up. Together, somehow, some way, we can keep fighting, not just for us but for future generations.

You are all heroes in just keeping on, keeping on in spite of all the challenges. Along with you, I am a proud member of CDR and the Disability Civil Rights Community.

CDSS PROPOSED CHANGES IN REGULATIONS

(Cont. from page 3)

crop of care providers to fill a shortage of caregivers?

These terrible regulations proposed by CDSS must be withdrawn from consideration. Let's put the care back into caregiving, and not criminals into caregiving for our most vulnerable!

TRAVELING WITH A DISABILITY IN HAWAII

(Cont. from page 3)

The town of Kaanapali, where our hotel and others are located, provides both trolleys which take you around the resort area and Whaler's Village (shopping center), and also a shuttle bus which takes you further into the town of Lahaina and possibly other nearby towns. As we had rented a car, I did not get to try the shuttle. My mom and I did use the trolley one day to go shopping at Whaler's Village. I believe the trolley runs once an hour, and all trolleys are wheelchair accessible. The one issue I had with the trolley was that they do not tie your wheelchair down. As I was in a very light power chair (about 55 pounds), I did not feel very safe. I quickly decided to wedge my wheelchair between the poles which lined the pathway to the seats; my mom and I were in the back of the vehicle, so I was not blocking anyone's passageway. Having my chair positioned this way would keep me from tipping over sideways, when the driver made sharp turns. We asked the driver if they

ever secure wheelchairs, he replied that they were not in the practice of doing so.

The town of Lahaina was fairly accessible. It is an old town, so not every shop has wheelchair access; most do though. Some of the sidewalks are cracked, and some driveways/curb cuts are not as smooth as they should be. On two instances, my wheelchair lost control and slid down the driveway/curb cut into the street. Even though I tried to maneuver back upwards, the awkward slope would not let me. This is one disadvantage of having a lightweight power chair!

On the last evening of our trip, we took a sunset dinner cruise. We inquired about accessibility on the boat; the first company said flat out no, however the second company said that they were happy to accommodate with anything I would need. When it was time to board the boat, I was ready to get out of my chair when the crew told my family and I that they could just lift me in my wheelchair onto the boat. Thankfully I am not very heavy and being in a lightweight chair, I felt confident that all would go well. Within a few minutes, three of the crew members plus my brother had me on the boat, rolling around comfortably in my own wheelchair! The dinner cruise was unforgettable, to say the least, and I will definitely take another, either in Hawaii or here in California. Happy sailing!

EVV UPDATE

(Cont. from page 4)

network and further shrinks the chronically inadequate pool of available employees. Often working at minimum wage, PCAs are reluctant to be geo-located during their work day, to be biometrically identified, or to take a job requiring technology skills without increased compensation and at the risk of providing quality care. Some employees are cautioning consumers they will leave once subjected to EVV. Potential workers are going elsewhere when they learn that GPS or biometrics are required. **Individuals with disabilities across the country are facing increased provider shortage because states are not prohibited from utilizing GPS and biometric features under EVV.**

- People with disabilities have a right to transparency and access to any private data that is collected from their lived experiences. **The burgeoning EVV industry is not forthcoming about the type of data it collects and stores.** Data compromise and loss prevention plans must include immediate

notification of any breaches to consumers and providers. Threats to identity protection and digital privacy should be given the highest accountability priority.

- **NCIL believes that people with disabilities have the right to control our own destinies.** If individuals are to make informed decisions, it's imperative that CMS and states create and implement comprehensive outreach and education to consumers and providers about EVV choice options, such as web portals, telephony, mobile apps, etc.

***What is EVV?** Electronic Visit Verification (EVV) is a technology-based system used to electronically verify that a personal attendant provides services for a client. The 21st Century Cures Act, federal legislation signed into law in December 2016, requires that all states implement EVV for Medicaid-funded home health care and personal attendant services. This law outlines the requirements that states must meet, but provides little guidance on how states can fulfill the requirement. EVV systems must verify: (1) type of service performed; (2) individual receiving service; (3) date of service; (4) location of service; (5) individual providing the service; and (6) time the service begins and ends.

MASTER PLAN ON AGING

(Cont. from page 4)

- California Health and Human Services Secretary Dr. Mark Ghaly makes appointments to Master Plan for Aging Stakeholder Advisory Committee - California Health and Human Service: <https://www.gov.ca.gov/2019/06/10/governor-gavin-newsom-calls-for-creation-of-a-master-plan-for-aging/>

THANK YOU!

- Many thanks to all those who paid their membership dues over the past month! You have made our membership drive a success!
- If you have yet to renew, please visit <http://www.disabilityrights-cdr.org/membership/appandfees.html>, or submit the attached application by mail.
- Please contact Kathleen at kdbarajas@icloud.com, if you have any questions or comments.

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 C/O Kathleen Barajas, President
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