

A Downward Spiral

*IHSS from its inception to EVV
from its leading expert and historian*

The continuing decline in services to the most vulnerable Californians, with the consent of a non-responsive legislature and an ivory tower bureaucracy.

California's In-Home Support Services (IHSS) was once the model for the United States. IHSS began in the 1970s, and was based on a social services model. Adults with significant disability, and limited income, could enroll in the program. This allowed those with significant disability to live in the community and become an integrated part of that community. IHSS improved the lives of thousands of people, who before IHSS were often consigned to nursing homes. IHSS also saved the tax paying public many, many millions of dollars.

IHSS was, and was intended to be, based on a social services model. The County Welfare Directors Association program overview says, "IHSS by its very nature is a consumer-driven program. The goal of IHSS is to maintain consumers' quality of life by providing assistance that enables them to remain safely in their own homes," and, "County IHSS social workers meet directly with the consumer and evaluate what the consumer can and cannot do for him/herself. While the scope of services is determined by program regulations, it is the consumer who decides how, when, and in what manner those services will be provided."

About a dozen years ago this cost effective and humane program was hijacked by forces that had little, if any, knowledge of IHSS recipients. Some of these forces wanted to end the IHSS program entirely, and other forces wanted to change it into a managed care, medical program.

The first assault came in the form of "fraud" charges. People who had never met, or even talked to an IHSS recipient, claimed that there were, "rampant abuses of the IHSS system" and the program was, "an employment program for ex-felons." These charges were proven false, but the California Senate and Assembly continued to pass laws that undermined the ability of IHSS recipients to live safely in the community.

In the rush to do something about "rampant fraud", legislation was hastily crafted, often buried in the middle of other legislation that had little relevance to IHSS. One piece of legislation, authorizing anti-fraud efforts, at least was honest. The legislation summary included this paragraph:

According to the author, notwithstanding quality assurance measures implemented through SB 1104, "insinuations of widespread fraud persist." The author suggests that these insinuations may be unjustified, noting that there may be a "disconnect between perception and fact" that is "not acceptable for such a large and growing state program. If we can identify fraud, we can stop it. But we can't diminish funding for the program based on anecdotal evidence."

"Anecdotal evidence?" A fiscally responsible and humane program is undermined by our elected officials because of "anecdotal evidence", and then these same legislators hide from those who are most affected by their actions! No person becomes significantly disabled to defraud the State of California! No person becomes a ventilator-dependent quadriplegic because they think it will be a ticket to a financial gravy train. This insinuation is degrading and libelous!

This absence of dialogue between legislators and those most directly impacted by IHSS rule changes is a disgrace! The members of the Senate and Assembly were being bombarded with negative information, but I can find no evidence that any legislator took the time to check this negative input with

a real IHSS recipient. The vast majority of our legislators have never met a significantly disabled IHSS recipient!

How did these actions impact IHSS recipients and their hardworking personal care providers? These new regulations made it harder to find and retain caring providers. The County Welfare Directors Association stated, "... it is the consumer who decides how, when, and in what manner those services will be provided." Program rule changes passed by legislators with little knowledge of the IHSS program, or those it serves, have made this nearly impossible! Where once we could find a personal care provider, hire and train him/her to meet our specific needs, we now must get approval from a faceless bureaucracy. It is no longer who we want, it is who a faceless bureaucrat approves! This is wrong ... and against State regulations!

The next burden to safe and independent living occurred when our legislature decided to contract with a multimillion dollar, for-profit company to "process" the IHSS timesheets and payroll. What had been a simple procedure became a nightmare! Timesheets were lost for weeks and even months. And, since this was a multimillion dollar company, it couldn't be their fault. It must be the fault of the IHSS recipients or their care providers. The recipients and providers received notices threatening them with penalties. These penalties, understood by recipients and providers as threats, included termination from the IHSS program.

Added to this bureaucratic nightmare was a change in the timesheet format. All IHSS recipients are thoroughly interviewed by county social workers. It is these social workers who determine the amount of help the significantly disabled IHSS recipient needs to remain safely in the community. They then convert this need into hours. These social workers use universal "time for task" guidelines. There were few problems until it was discovered that the multimillion dollar company, who had a lucrative contract with our State, couldn't process the current timesheets.

New timesheets were designed to conform to the inadequacies of this multimillion dollar company. And, although a county social worker had already determined the needed hours, the IHSS recipient and/or provider had to re-enter these hours into small boxes on the new timesheet. In addition, the hours have to add up correctly by week, even though the original hours were assigned by month! And again, if recipients and providers were unable to do the complicated mathematical computations correctly, they are threatened with penalties. These penalties included the threat of no payment. Payment that had already been earned! No other person in California is expected to do these complicated mathematical computations!

The straw that will break the camel's back is hovering over the IHSS program.

In 2016, Congress passed the "21st Century Cures Act". This Bill is over 300 pages and covers many topics, some related to health care. Buried deep within this Bill, in a section relating to mental health, is a mandate to begin electronic surveillance of people with significant disability. The exact title is: Section 12006. Electronic visit verification system required for personal care services and home health care services under Medicaid.

This section was added at the last minute, at the request of one Congressman, Brett Guthrie of Kentucky. He had tried to get similar legislation passed before, but it was always rejected. Who was asleep at the switch this time?

Electric Visit Verification, or EVV, is the equivalent of an ankle bracelet for significantly disabled individuals who need personal care assistance. Significantly disabled individuals, and their care providers, must have their movements tracked in the faulty, and libelous, assumption that anyone with a significant disability is cheating the government.

The “government”, and a for-profit private contractor, will know where the significantly disabled person goes, how long they stay at that location, and when they return to their home. This is based on two failed assumptions. The first is that people with significant disabilities are incapable of living meaningful lives and are unable to make their own decisions, and the second is that everybody with a significant disability is a crook!

These assumptions of incompetence and fraud, now imbedded in federal law, flies in the face of the Americans with Disabilities Act and the 1999 Supreme Court Olmstead decision. The Court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities. The Court also wrote, “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life.” and, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

Electronic surveillance will discourage the person with significant disability from leaving their home. Their home will become, in essence, an institution. If we leave our home, these “ankle bracelets” will tell the government, and the for-profit private contractor, where we go to worship, where we meet our friends, if we attend a political rally, and even if we enter another friend’s home.

This surveillance will kill the In-Home Support Services program. If a person with a significant disability is assumed to be incompetent and/or a criminal, why would they want to make the effort to live outside an institution? What incentive would they have to be an active member of their community? “Big Brother” will be watching all of the time! “Big Brother” will know if, when, and where they worship! “Big Brother” will know their associations, their recreation, their every move!

We know how this downward spiral began! What we NEED to know is how to stop it!

This paper is not an idle writing exercise. I am one of the Californians with significant disability who has been impacted by this downward spiral in the IHSS program. I happen to be a ventilator dependent quadriplegic. I have been disabled for more than sixty years. If it wasn’t for In-Home Support Services program I would have entered a sub-acute nursing facility many years ago, at more than ten times the cost to the tax paying public. Of course, if I had entered a sub-acute facility, even a good one, I would likely have died many years ago.

With the assistance of IHSS, I became a journalist and advocate. I was the 1988 Los Angeles County Volunteer of the Year, and I am a Certified Lay Servant in the United Methodist Church. Although I have nothing to hide, I do not appreciate a private, for-profit company tracking my coming and going.

I do not live in a totalitarian country ... I hope! In fact, in 2012, the United States Supreme Court ruled that installing a GPS tracking device on a vehicle and using the device to monitor the vehicle’s movements constitutes a search under the Fourth Amendment. This could not be done legally without a warrant or the consent of the individual. Some might think that an IHSS recipient, like me, would consent to this search/monitoring. Yes, I might, knowing that if I don’t consent I would be terminated from the program. But, the courts have ruled that this is coercion.

There are many thousands of Californians with significant disability who have similar stories. We did not become disabled to cheat the system! We did not become disabled to get a free ride! We pay taxes! We contribute to our communities in countless ways! And, we are struggling with a political structure that ignores us or wants to make a profit from us! This must stop!

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