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May 11, 2015

Honorable Jimmy Gomez  
Chair, Appropriations Committee  
California State Assembly  
Capitol Building, Room 2114  
Sacramento, CA 95814

**RE: AB 1518 (~~BROWN~~ Assembly Aging and Long Term Care  
Committee) – SUPPORT**

Dear Assembly Member Gomez:

Disability Rights California, a non-profit advocacy organization that advances and protects the rights of Californians with disabilities, is the sponsor of AB 1518. We strongly and enthusiastically support it and believe that it will save general funds.

This bill really came from our clients – people who want to stay out of or return home from institutional long term care settings and are unable to do so because of the outdated design and implementation of the Nursing Facility/Acute Hospital (NF/AH) waiver. The waiver is supposed to be a key tool in helping people receive care at home, beyond what they can get through the In-Home Supportive Services (IHSS) program. However, the problems with the waiver impede rather than assist people to get what they need, resulting in unnecessary institutionalization and other costs, human and monetary.

The outdated and unfair waiver and other state policies make it easier for somebody to get care in a more expensive and unneeded institution than to receive services at home. This is the definition of “institutional bias.”

Other states are way ahead of California in lessening their reliance on institutional care and lessening their expenditures on expensive and unneeded institutional beds. California has done virtually nothing to do either outside of the Developmental Disabilities system, which has done both with great success. We are paying for nursing home beds for people who want to leave them and we are, in effect, subsidizing the vacant nursing home beds insofar as fixed costs are built into the reimbursement methodology.

We should be working right now to meet the needs of the growing population of seniors and people with disabilities who will need Long Term Services and Supports and who do not want to go to an institution to receive those services.

The Americans with Disabilities Act (the ADA) of 1990 and the United States Supreme Court decision in Olmstead (1999) affirm that people with disabilities (which includes seniors and children) have the civil right to receive public services in the most integrated setting. Institutions are not the most integrated setting for most people, so public policy which favors institutions violates their civil rights.

It is time for this waiver to meet the needs of Californians, respect their civil rights and save taxpayer dollars which are being unnecessarily spent on high cost institutions.

**Background on the NF/AH waiver:**

Medicaid waivers allow states to deliver and pay for health care services with the federal government waiving some of the usual Medicaid requirements, such as “statewideness.”

Medicaid 1915(c) waivers allow states to provide long term care services in home and community based settings under the Medicaid Program. California’s NF/AH waiver “provides case management/coordination, habilitation, home respite, waiver personal care services, community transition, continuous nursing and supportive services, environmental accessibility adaptations, facility respite, family/caregiver training, medical equipment operating expense, PERS-installation and testing, PERS, private duty nursing including home health and shared services, transitional case management for medically fragile and technology dependent individuals age 0 - no max age.”<sup>Endnote 1</sup>

Even with the movement of Medi-Cal long term services and supports into managed care through the Coordinated Care Initiative, the Nursing Facility/Acute Hospital (NF/AH) waiver provides virtually the only home and community-based alternative to nursing facility placement for people who require skilled home care or services beyond In Home Supportive Services (IHSS).<sup>Endnote 2</sup> While this waiver has great potential, California has made choices which significantly limit the NF/AH and which create unnecessary and costly barriers to community living for eligible individuals. We specify those problems below.

**Background on the EPSDT “Cliff”:**

Children with the most significant medical needs can live at home with the support of home nursing. For Medi-Cal eligible children under age 21, Early and Periodic Screening, Diagnosis and Treatment (EPSDT) funds this nursing. Home nursing hours are calculated based on the appropriate institutional level of care equivalent. For example, a child eligible for nursing facility level B will be eligible to receive in-home nursing hours up to the cost of the pediatric nursing facility level B.

At age 21, Medi-Cal recipients should transition from EPSDT home nursing to home nursing funded by the Nursing Facility/Acute Hospital (NF/AH) waiver, the Developmental Disabilities (DD) waiver, or regional center services. Unless needs have changed, this transition should be seamless and services should not decrease. Some individuals have experienced a devastating reduction in hours because of the different ways the DHCS-administered NF/AH waiver program operates, including lower caps on hours and more restrictive level of care criteria.

For regional center consumers, the issue is further complicated because the Lanterman Act includes an entitlement to services which is uncapped. Because the 2009 Amendments to the Lanterman Act required the use of generic resources including Medi-Cal, regional centers require consumers to seek in-home nursing through the NF/AH waiver, including filing questionable appeals, before regional centers will fund in-home nursing to supplement the often meager allotment provided by the NF/AH waiver. If consumers are placed on the DHCS NF/AH waiver, additional nursing services must be purchased by the regional center with state-only dollars because individuals can only be on one HCBS waiver (e.g., NF/AH waiver or DD waiver but not both).

**Specific problems and solutions:**

**Too few waiver slots:** Approximately 20,000 nursing home residents say they are interested in returning to the community, in answer to a question in the Minimum Data Set, which is administered quarterly in nursing homes. The latest studies show there are about 10,000 people with low care needs in California nursing homes. However, there are only 3,792 waiver slots to serve those who want to get out of nursing homes or other institutions and those already out who want to stay out. Approximately 700 people, living at home and qualified for nursing home care, are waiting, for years, on the waiver wait list.

**Fix:** Add 5,000 "slots," with further additions based on need, as determined by several specified factors.

**Individual cost cap:** Federal law requires that the overall cost to serve all the people on the waiver does not exceed the cost of serving that population in institutions. California has an individual cost cap, which the federal government does not require. This causes several problems. When costs increase for a service, such as IHSS wages, which is paid for from the individual waiver budget, consumers already at their cost cap lose otherwise authorized and needed services to "pay" for the increase. For certain individuals who need significant in-home care the low cost cap may mean the difference between remaining at home or being removed from home and family and forced into a more costly, less desirable and unnecessary institutional placement. Many other individuals are served well below the cost cap. Instead of using those savings to offset costs for people who need more, the state denies needed services to them and scores savings to the General Fund.

**Fix:** Use an aggregate cost cap, as is done in the Developmental Disabilities (DD) waiver that serves more than 100,000 clients.

**Outdated "cost caps":** The cost caps are biased in favor of institutional care, which prevents some people from receiving needed waiver services. For instance: the state pays about \$72,000 a year for a nursing home bed, but allows only \$48,000 for comparable services in the consumer's home. The state pays \$151,821 for a NF-Distinct Part bed, but only \$77,600 for that care in the community.

This chart shows outdated figures from 2014; institutional rates are now higher in some levels of care.

<b>Institutional Level of Care</b>	<b>Annual Institutional Rate</b>	<b>Annual Waiver Cost-Cap (Current in 2012 Waiver)</b>
Nursing Facility (NF)-A	\$34,388 (2012)	\$29,548
Nursing Facility (NF)-B	\$68,074 (2014)	\$48,180
NF-B Pediatric	\$110,280 (2012)	\$101,882
NF-Distinct Part	\$151,821 (2013)	\$77,600
NF-Subacute, Adult	\$320,991(2013, no vent)	\$180,219
NF-Subacute, Pediatric	\$282,574 (2012)	\$240,211
Acute Hospital	\$437,757 (2012)	\$305,283

**Fix:** Base the aggregate cost cap on comparable institutional rates.

**Slow waiver approval process:** The waiver approval process takes so long that people who could go home are sent to nursing homes or other institutions from hospitals.

**Fix:** Establish an expedited waiver approval process for people in danger of going to institutions.

**The dangerous: EPSDT “cliff”:** Because of different rules and rates for EPSDT and NF/AH waiver services, many young people with significant disabilities and high care needs lose half or more of their services when they turn 21 and switch from EPSDT to the NF/AH waiver. This endangers their health and may force them into an institution even though they have a family that wants to keep them at home.

**Fix:** Ensure that young people continue to get the services they need when they turn 21.

This year is the 25<sup>th</sup> anniversary of the ADA – the civil rights bill for people which says Californians have a right to stay out of institutions.

This is the year to do the right thing for Californians who need long term services and supports and want to stay out of institutions and for California taxpayers who are paying for that high cost institutional care.

Thank you for your consideration.

Very truly yours,



Deborah Doctor  
Legislative Advocate  
Disability Rights California

~~cc: Honorable Cheryl Brown, California State Assembly~~  
~~CC: Robert MacLaughlin, Chief Consultant, Office of Assembly~~  
~~Member Brown Assembly Aging and Long Term Care Committee~~  
Honorable Members, Assembly Appropriations Committee  
Lisa Murawski, Principal Consultant, Assembly Appropriations  
Committee

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Endnote 1: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915%20%28c%29#wavers>  
Endnote 2: The NF/AH waiver is an umbrella for three distinct waivers (Nursing Facility-A/B (NF-A/B), Sub acute, and Acute), each with distinct eligibility criteria.