Congress of the United States

Washington, DC 20515

November 13, 2023

Honorable Gavin Newsom Governor of the State of California 1303 10th Street, Suite 1173 Sacramento, CA 95814

Dear Governor Newsom:

As California Congressmembers in the U.S. House of Representatives, we write to you regarding the Home & Community-Based Alternatives (HCBA) Waiver.

Improved and expanded Medicaid-funded Home and Community-Based Services (HCBS) is a priority for the for the undersigned Members. Members of the California Congressional Delegation previously wrote to California Department of Health Care Services (DHCS) Director Baass on September 16, 2021, recommending that the State of California increase the number of people served by the HCBA Waiver.¹ We believe the need for more HCBA Waiver slots is even more urgent now, with over 3,000 medically fragile children, seniors, and people with disabilities on a waiting list² for this critically important program.

1. Background

The HCBA Waiver³ is a Medi-Cal HCBS program which serves children, adults, and seniors with disabilities who qualify for an institutional level of care and need home and community-based services to live at home in the community. This waiver is the only community-based service option for people with significant disabilities, including most medically fragile children who do not qualify for Regional Center services. Part of the importance to the under 21 population served by the HCBA Waiver is the availability of institutional deeming,⁴ which ensures that medically complex children can access Early and Periodic Screening, Diagnosis, and Treatment (EPSDT)⁵ services and protections, given that this is the only 1915(c) Waiver in California for children who do not have Intellectual or Developmental Disabilities.

In addition to children, the HCBA Waiver serves people with disabilities, including seniors. The HCBA Waiver is particularly critical for people who need nursing care and for people who need more than the maximum number of In-Home Supportive Services (IHSS) hours (283 hours per month). The HCBA Waiver enables people to receive 24-hour care in their homes, a lifeline for seniors with disabilities like Alzheimer's disease and dementia who often need more care than IHSS offers.

¹ <u>https://barragan.house.gov/wp-content/uploads/2021/09/HCBA-Comments-Letter-Final-09-16-21.pdf</u> ² <u>https://www.dhcs.ca.gov/services/ltc/Documents/HCBA-Monthly-Dashboard-Sept2023.pdf</u>

³ Section 1915(c) of the Social Security Act (42 U.S.C. § 1396n(c)) allows the federal government to waive certain provisions of Federal Medicaid law to allow states to provide home and community-based services in lieu of institutional care to qualifying individuals.

 ⁴ Institutional deeming means Medi-Cal treats a child as if they are in an institution, which means they are their own budget unit, and their parents' income and resources are not considered in financial eligibility.
⁵ EPSDT is a Medi-Cal benefit that provides a comprehensive array of preventive, diagnostic, and treatment

^o EPSD1 is a Medi-Cal benefit that provides a comprehensive array of preventive, diagnostic, and treatment services; including, but not limited to, case management for individuals under 21 years of age, as set forth in Section 1905(r) of the Social Security Act (42 U.S.C.7 §1396d(r)).

In recent years, we have heard that waiver agencies, regional centers, managed care plans, and organizations serving unhoused individuals have become more aware of the unique benefits of the HCBA Waiver program. As a result, there has been a tremendous increase in applications for the program over the last five years. Between 2022 and 2023, there was a 3,500 person increase in the total number of people either on the Waiver or on the waiting list.⁶ Currently, the HCBA Waiver is capped at 8,974 and as of October 2023, the Waiver is full, with more than 3,000 people on the waiting list.⁷

Now that the HCBA Waiver cap has been reached, we understand that DHCS plans to submit an amendment to CMS to increase the limit as of January 2024 to 10,081 slots because there is an existing California budget allocation for that number of slots. We do not believe this modest increase will provide immediate access to Medi-Cal for medically fragile children, clear the waiting list, or accommodate the obvious increase in consumer need for the program. If the state does not request a meaningful increase in slots, we are concerned that thousands of Californians will languish on an ever-growing waitlist and suffer unnecessary institutionalization.⁸

2. Impacted Individuals

We believe there is a critical need to increase HCBA Waiver slots by a meaningful and sufficient amount. The right to services which enable seniors and people with disabilities to lead full lives, on an equal basis with those living without disabilities, is undisputed, recognized by the Supreme Court's *Olmstead* decision and California law. In terms of cost, the HCBA Waiver saves California money: the average cost of HCBA Waiver services is \$47,728 per year, per person while the average cost per year of a skilled nursing facility (SNF) for the HCBA Waiver population is \$128,832.⁹

This is also an equity issue. Underfunding HCBS is particularly impactful for underserved communities of color.¹⁰ It is well-documented that people of color are impacted by the failure to create a robust HCBS stem. An August 2022 study by the UCLA Center for Health Policy Research examined the need for HCBS at home, and documented the harm caused by unmet needs among adults. This study found that more than half of the older adults and people with disabilities who were surveyed reported needing help from another person for routine care, while about 1 in 5 reported needing help with personal care. For both groups, 2 in 5 respondents reported that they could use more help or that they get no help at all. The study also found that "Black/African American and biracial/multiracial respondents were among those most likely to report needing help with routine care (73.5% and 72.4%, respectively) and with personal care (39.4% and 22.5%)."¹¹

3. Recommendations

https://www.sciencedirect.com/science/article/abs/pii/S1525861021002437

⁶ <u>https://www.dhcs.ca.gov/services/ltc/Documents/HCBA-dashboard-Jan2022.pdf</u>

⁷ <u>https://www.dhcs.ca.gov/services/ltc/Pages/HCBA-Waiver-Current-Enrollment-Dashboard.aspx</u>

⁸ <u>https://calmatters.org/health/2022/01/california-nursing-homes-transition/</u>

⁹ <u>https://www.dhcs.ca.gov/dataandstats/reports/mcestimates/Documents/2023_May_Estimate/MAY-2023-Medi-Cal-Local-Assistance-Estimate.pdf</u> at 773

¹⁰ *Fact Sheet: The Biden-Harris Administration*, 2023, <u>https://www.whitehouse.gov/briefing-room/statements-releases/2023/02/23/fact-sheet-the-biden-harris-administrations-work-to-support-black-disabled-americans/; see also, Medicaid Reimbursement Rates Are a Racial Justice Issue | Commonwealth Fund; see also, <u>https://www.nber.org/bh-20193/increased-medicaid-reimbursement-rates-expand-access-care;</u></u>

¹¹ Kietzman, Kathryn and Chen, Lei. *Health Policy Fact Sheet*, UCLA Center for Health Policy Research, 2022, <u>Unmet-Needs-for-Help-at-Home-factsheet-aug2022.pdf (ucla.edu)</u>

We ask that California consider allocating funds in the FY 2024 Budget to allow for an increase in the number of HCBA waiver slots sufficient to clear the current waiting list *with* the ability to raise the cap as needed to meet demand for this program.

California can do this in the same way that it operates two other 1915(c) Waivers for individuals with Intellectual and Developmental Disabilities (IDD), as neither the HCBS-DD nor the Self Determination Program (SDP) Waivers have functional caps.¹²

We believe that it is critical that California increase the number of HCBA Waiver slots, so seniors and people with disabilities can remain in their homes and communities and live with dignity and independence.

Thank you for your consideration of our recommendations.

Sincerely,

Manette Diar Barn

Nanette Diaz Barragán Member of Congress

Zoe Lofgren Member of Congress

Barbara Lee Member of Congress

Katie Porter Member of Congress

Mike Thompson Member of Congress

¹² Both the HCBS-DD and Self Determination Waivers, (which are only available to Regional Center Consumers with I/DD) contain the following language:

"California will submit necessary DD/SDP Waiver amendments to accommodate all individuals who are eligible for and express an interest in participating in the SDP /[HCBS-DD] Waiver should the approved SDP/ [HCBS-DD] Waiver capacity be insufficient to accommodate all interested persons." https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/81096 at 33.

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Page 5

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