

# Hold Private In-home Respite Companies Accountable for the Public Funds They Receive

SEIU Local 2015 members call on the California State Legislature to support [Assembly Bill 1380](#) to improve accountability in the respite system. Respite is publicly-funded, temporary care for people with a developmental disability. The program helps to relieve family caregivers for a few hours a month from the constant, demanding responsibilities of providing care. Respite care is not a luxury, it is a necessity for people who provide care around-the-clock, and allows them to keep their loved ones at home.

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## The Problem

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In FY 2015-16, California spent more than **\$221 million on in-home respite services** with little accountability for companies that are making millions in revenue from this public money.

- Respite companies have no limit on how much they can spend on administrative costs and often make huge profits at the **expense of the workers who provide respite**
- Respite companies are not required to submit their cost reports to the state but make millions in revenue from Medi-Cal funds
- This lack of oversight is taking place despite the fact that respite hours are capped and many families **do not receive enough respite hours** meet their needs

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## The Solution: AB 1380

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This bill will:

- Require an in-depth review of rates the state pays to companies to ensure they are reasonable, and to report the findings of this review to the Legislature
- Reveal how respite rates are spent to produce public data on the costs of doing business in the respite system- including wages and benefits of workers
- Ensure that regional centers are reviewing vendor contracts regularly to maintain updated and accurate information

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## How do Individual Respite Care Companies Measure Up?

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## Inland Respite

- Has the highest full service rate of \$25.26 per hour, and retains 12% of this rate in net profit- the most of any major company audited in 2016 <sup>i</sup><sup>ii</sup>
- Spent almost 30% on administrative costs and retained over \$800,000 in public funds in profit in 2014-15 <sup>iii</sup>

## Accredited Nursing <sup>iv</sup>

- Spent almost 20% on administrative costs in 2014-15
- Made almost \$900,000 in profit from public funding for in-home respite, more than any other company audited in 2016

## Premier

- The company's administrative spending on its full service rate is nearly 40%, the highest full service administrative spending of any of the four companies audited <sup>v</sup>

## In-Roads Creative Program Inc.

- The company made **44% in net profit from its full service rate in 2014-15**, almost four times more than the next highest profit-retaining company, Inland Respite Inc. <sup>vi</sup>

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## Member Stories

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*Feda and her son  
Muhammad*

### **Feda Almaliti—Fremont, CA**

Feda lives in Fremont, CA and is a caretaker for her 12 year-old son Muhammad who has severe autism. For nine years, Feda has received respite services from the Regional Center of the East Bay. Respite has allowed Muhammad to stay in a healthy and safe home with a family who loves him. Feda and Muhammad's daily routine starts every day at 5:30am when Muhammad wakes up and needs to get ready, which can take a long time. Each day Feda helps Muhammad get dressed, assists him in getting downstairs, makes him breakfast, helps him eat his breakfast and reminds him

to slow down, makes sure he doesn't hurt himself, and gets him ready for school for kids with severe autism. This is just the first hour or two of the day.

***"These kids need constant care, my son needs to be in somebody's line of sight at all times. It can be emotionally exhausting. There are studies showing that parents of children with autism have the same stress levels as soldiers in combat"***

**Feda Almiliti**

Respite care allows Feda to take time to herself to do normal things that anybody would need to do to unwind to be emotionally healthy. Feda has struggled to find qualified respite providers and does not receive enough of the hours that she needs. AB 1380 could help Feda by requiring that the majority of respite rates go towards direct services like training to hire and retain qualified respite workers.

### **Brenda Oliver—Fresno, CA**



*Braelon and his respite care provider*

Brenda is an IHSS provider in Fresno for her 22-year old son Braelon, who has autism. Brenda provides around-the-clock care for her son, who needs to stay with her while doing all her daily tasks and errands. Brenda describes Braelon as a great son who is really particular about his dental hygiene, hand hygiene, and environment. Brenda and Braelon's daily routine includes consistent promptings/ instructing and protective supervision, because of Braelon's deficits in social interactions and communication, as well as repetitive behaviors and interest. Braelon is passionate about media and music.

***"Respite is important because I don't get a day off, I don't get a break or sick time, or vacation and respite affords me time out. This is work and it's an honest job. I am very thankful that I have the ability to care for my son, but it does not afford me time off like any other job would."***

**Brenda Oliver**

While Braelon is a driven and smart young man, Brenda's job is very consuming and exhausting. She home-educated her son and is going out of her way to prepare him to go to college. Braelon performs well below his peers socially, functionally and academically, and around-the-clock care can be emotionally stressful. Brenda needs respite to be able to take care of her own well-being. Receiving respite care allows Brenda to be involved in the community of people who take care of loved ones with developmental disabilities. She goes to trainings, webinars, and conferences to familiarize herself with different resources and be a better advocate for disability rights. Brenda does not think she receives enough respite hours each month. AB 1380 could help expand the availability of respite workers by

improving their wages and benefits so that people like Brenda can get the time that they need to take care of themselves while providing round-the-clock care to their loved ones.

### **Robert Brown—Shasta, CA**

Robert Brown is a Local 2015 member who lives in Shasta, CA and is a provider for his 13 year old son who has high-functioning autism. Robert spends 11-12 hours a day caring for his son and helping him get through his daily routine. Respite services allow Robert and his wife to spend time together and have a few hours to a month to recharge to avoid becoming burnout from the tremendous amount of work they do in raising a son with autism.

*"To say that it's tiresome is to understate it. We live in a constant state of weariness. We're just exhausted emotionally, spiritually, and physically and that's why we need respite."*

**Robert Brown**

While Robert has been receiving respite care through Far Northern Regional Center since 2005, he does not receive the amount of hours he needs to support his son. In Shasta County, it has been very difficult for Robert to find a respite worker in his area. With a shortage of respite providers and a limit on the amount of miles the Regional Center will pay for, Robert sometimes pays out of pocket for mileage expenses for respite workers. AB 1380 will improve respite jobs, helping to increase the amount of respite providers and allowing families to find respite providers in their area.

<sup>1</sup> California Audit Report 2016-108 pg. 23

" Companies audited in 2016 refers to the respite vendors studied by the California State Auditor as part of its investigation of in-home respite services administered through regional centers. These vendors made more than \$7 million in FY 2014-15

<sup>iii</sup> California Audit Report 2016-108 pg. 26. Data comes from company's Full Service Rate

<sup>iv</sup> Ibid

<sup>v</sup> California Audit Report 2016-108 pg. 23

<sup>vi</sup> Ibid