

To: Legislative and Public Policy Committee
From: Karen Mulvany
Re: Written Public Comment for 5/8/2019 meeting
Date: 5/6/2019

The following is public comment pertaining to select bills that the LPPC is supporting.

1. AB-1169 Personal income taxes: credit: employer: qualified wages.

I support this bill, but would recommend including additional provisions to protect workers that may not be aware of SSA regulations from inadvertently losing their SSI benefits.

Per Social Security Administration guidance at https://www.ssa.gov/OP_Home/cfr20/416/416-0905.htm "The law defines disability as the inability to do any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." The substantial gainful activity income threshold for SSI eligibility can be seen at <https://www.ssa.gov/OACT/COLA/sga.html> ; in 2019, the SGA income threshold is \$1220 per month.

A credit of 40% of the employee's wages not to exceed \$6000 a year, as recommended in this bill, would equate to maximum subsidized employee wages of \$15000/yr, or \$1250 per month. Attaining this income would be \$30 above the limit where SSA would no longer deem an SSI beneficiary to be disabled. This could result in adverse consequences if the beneficiary's employment subsequently ceases. Ideally such risks should be anticipated and mitigated within the bill itself.

Trial work periods where SSI beneficiaries can still retain SSI benefits while trying out a job are explained at <https://www.ssa.gov/OACT/COLA/twp.html>:

"During a trial work period, a beneficiary receiving Social Security disability benefits may test his or her ability to work and still be considered disabled. We do not consider services performed during the trial work period as showing that the disability has ended until services have been performed in at least 9 months (not necessarily consecutive) in a rolling 60-month period. In 2018, any month in which earnings exceed \$850 is considered a month of services for an individual's trial work period. In 2019, this monthly amount increases to \$880."

Suggestions:

- For SSI beneficiaries that do not wish to lose their existing SSI benefits, consider:
 - a. Ensuring that during the trial period of any duration, employers will initially set wages below the SSI trial work period thresholds (of \$880 a month in 2019), which may be implemented through part time work schedules .
 - b. Optionally, for those employees that wish to earn compensation above the trial work period threshold amount (of \$880 a month in 2019), but below the substantial gainful activity level of income (at \$1220 a month in 2019), require that the employer ensure that the total number of trial work period months, including any such months historically completed by the employee at other jobs, will not exceed 9 months in a rolling 60 month period.

- For SSI beneficiaries that do not wish to lose their disability status at SSA, consider a requirement that employers cap compensation during the subsidized work period at just below the substantial gainful activity level (\$1220 per month in 2019).
- Consider setting permanent job offer requirements so that SSI benefits after a subsidized trial work period ends are not lost, if the employer decides not to continue employing the beneficiary. In other words, for an employee who is earning more than the monthly trial work period amount, at no later than 8 months, require that the employer offer or decline to offer the employee employment at compensation level above the substantial gainful activity amount after the subsidy ends.

2. AB-536 Developmental services.

I support this bill. Please consider changing, in section 4512(a), “originates” to “originates or, originated.”

This change would clarify that an individual older than 22 may still qualify for regional center services if it can be established that the qualifying disability or disabilities commenced prior to 22.

Recent studies indicate that females with autism are diagnosed later than their male peers, often into the late twenties. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5040731/>

3. AB-813 Developmental services: alternative dispute resolution

I support this bill, with modifications. The proposed legislation as currently proposed will only address disputes about services and eligibility, not rights violations. I would strongly recommend that rights violations be included in the alternative dispute resolution system, potentially to be decided by the proposed Council itself.

The standing dispute resolution system is divided into two types of complaints with separate dispute resolution processes:

- rights violations (section 4731 complaints, which are decided by DDS) or
- complaints about eligibility or services, which are decided by 3 processes, namely
 - A) Informal Conference (decided by the regional center),
 - B) mediation (decided by an ALJ, in a private decision) or
 - C) Fair Hearing (decided an ALJ, in a public decision).

On behalf of my daughter, I have argued 4 regional center Fair Hearings, three of which were adjudicated and one of which was settled. After the first Fair Hearing, the regional center hired outside counsel to represent them on two subsequent occasions. The Fair Hearings required hundreds of hours of research and document preparation, and the wherewithal to appear in court, and parry the tactics of opposing counsel. I always appeared alone, without counsel for my daughter, as there was no other option. Having managed teams of lawyers in a negotiated disputes in my past work history, this was feasible work for me, but it was extraordinarily challenging. It is simply incredible (meaning, not credible) that consumers and families are expected to navigate and argue such issues alone.

On my daughter's behalf, I have also filed three 4731 rights violation complaints. In every case, the rights violation was associated with a service issue. It places a severe burden on the consumer or family to have to separate the rights and service denial issues and contest them separately. In practice, one must obtain a right violation finding first, then showcase the DDS decision in the Fair Hearing to provide the ALJ with assurance that a regional center problem exists, a process that can take the better part of a year, and result in a further delay in services. For most consumers and families who lack legal assistance, this complex process is practically impossible.

The Lanterman Act and Title 17, and the Title 22 regulations that Title 17 regulations rest upon, are complex. They are made 20 times more complex by the policy variation that is allowed within each regional center by virtue of the Lanterman Act itself. Half or more of the disputes that our family has experienced with our own regional center have seemingly arisen from a regional center lack of understanding of the law, as regional center personnel get wrapped around the axle of their own unique policies. Others have seemingly arisen because the regional center does understand the issues but requires an adjudicated opinion on a complex topic, and then there are those that arise from actions that "defy explanation" in the words of one ALJ. Consumer and families need help with all of them.

For many consumers and families, these disputes are intensely emotional, exacerbated by anxiety, hope and fear. They often feel deeply wronged. There is no escaping the legitimacy of those feelings, and yet such emotion is almost always savagely counterproductive in the courtroom and in mediation. Left alone without assistance, and overwhelmed by emotion, the deck is stacked against them. Consumers with intellectual and developmental disabilities and their families need help.

In past years, one could go online to find the Fair Hearings that were requested but dismissed because the complainant (consumer/family) was a no-show, so one could get a sense of how many families tried to get a fair hearing to resolve a dispute but could not muster the documents and other preparation required of them to proceed. However, this information is no longer reported online. There is no telling how many consumers and families have lost services due to a lack of dispute resolution assistance.

Suggestions:

It is not entirely clear whether this new dispute resolution system will initially supplant or augment the 3 dispute resolution options in place for services and eligibility disputes. Presumably it will augment it for now, pending future legislation, until the efficacy of the new system is known, but it would be helpful to clarify this.

With respect to composition of the Council, such a Council should include Disability Rights and a DDS Representative. It should include an ARCA Representative. The Chair of the State Council should have the authority to appoint a representative, as this work could be overwhelming. A demonstrated knowledge of the applicable laws and regulations should be required of all Council members. Council memberships should be staggered so expertise is not lost in a giant wave of new membership.

All Council disputes and decisions should be publicly disclosed, with adequate privacy protections for the consumers and families. This will be the most important change that the Council could implement, as only fair hearing decisions are made public today. Sunshine is the best medicine.

Please consider additional changes:

- All informal conferences should be recorded, and at the option of the consumer, transcribed. It is vital to the record to ensure that the consumer and family have not been misled in these meetings. At present, the regional center is solely tasked with summarizing the meeting and making the decision.
- Today, rights violations must be separately filed as a 4731 complaint to DDS, which unfortunately is empowered with few compliance options. Because regional centers are effectively independent contractors, DDS can only terminate its contract or a portion of its contract with a regional center, or make requests of the regional center. Given that each regional center is a monopoly provider, DDS will of course never exercise the nuclear option and terminate a regional center contract over a rights violation. In the case of adequate notice violations, DDS will typically request that the regional center retrain its staff. In our experience, this was not effective in preventing the same violation from immediately occurring again, even in the face of a court order. We also discovered that violation of a court order was not something that could be addressed through either the fair hearing process or through a 4731 complaint. It is not clear that any entity presently has the authority, as a practical matter, to address rights violation issues in a way that is likely to result in compliance.
 - Instead, rights violations should be reported the Dispute Resolution Council, and the issue and decision should be publicly disclosed, with identifying consumer information redacted or replaced, as are Fair Hearing decisions. I believe the prospect of public disclosure is the least costly and best option to reduce future violations.
- Another issue is that regional center staff can testify in Fair Hearings that they have a policy pertinent to the dispute that gives them the authority to behave as they did, even when the stated policy is not publicly disclosed, nor has ever been reviewed by DDS. Instead, regional center should be prohibited from using, as a basis of denial, a policy that has not been publicly disclosed and approved by DDS. Another proposed bill, AB 1643, addresses this issue.

4. AB-216 Pupil discipline: restraint and seclusion.

Great bill; let's move to one bill of student rights. With the transition to full inclusion in school settings, we must achieve uniform standards of care and rights for both exceptional needs and general education pupils, so that teachers and staff are not confused about which standard applies. In no events should the rights and protections available to exceptional needs students be less robust or extensive or safe than those available to general ed students.

5. AB-823 Developmental services.

I support this bill.

For 4696.1(f), consider additionally specifying that the regional center's Home web page shall include a prominent active link to an emergency or crisis web page, where the emergency or crisis contact information shall be prominently displayed with live links, as specified. Ideally this web page should state that per this section, the services must be available, and that if services are unavailable, the regional center must issue an NOA to the client and report it to DRC. If the lack of availability is due to

lack of funding, the regional center must issue an NOA to the consumer and a notice to DDS which must then notify the legislature.

6. AB-1172 Special education: nonpublic, nonsectarian schools or agencies.

Awesome bill. I would also advocate that all general Ed teachers and staff should be trained in ABA as well, given movement towards full inclusion — but that would be another bill.

7. AB-1643 Developmental services.

Fantastic bill and desperately needed.

In one Fair Hearing that I argued on behalf of my daughter, a regional center manager testified to a wide variety of undisclosed policies to support a denial of services, including a policy that if a licensed residential facility was being run by a couple, they only counted as one staff. Though the ALJ rejected this testimony, another might easily have accepted it.

8. SB-398 Protection and advocacy agency.

I truly appreciate the good intent behind this bill, but I am very concerned about how this is written, especially given that it may obligate families to provide supports that government should be providing, but has failed to.

Having experienced multiple instances where regional center services, MediCal Services, and SSI benefits have been improperly delayed, denied, or withheld, I fear that any implication that the family must step in to fill the gap endangers entitlement, and the qualifying individual's right to those benefits.

My fear is that this bill makes responsible parents guilty of neglect under section (g), even in the face of inadequate government funding and inadequate government provision of needed supports and services, because they have stepped in to provide services, supports, or other assistance that caused, or may have caused:

“injury or death to an individual with a disability or that placed an individual with a disability at risk of injury or death, and includes, but is not limited to, the failure to establish or carry out an appropriate individual program plan or treatment plan, which includes a discharge plan; provide adequate nutrition, clothing, or health care to an individual with a disability; or provide a safe environment, which may include failing to maintain an adequate number of trained staff or failing to take appropriate steps to prevent self-abuse, harassment, or assault by a peer.” *If a family steps in to provide uncompensated support, because the regional center is not providing the support that is needed, and the family member simply cannot provide the support necessary to prevent self-abuse, is it appropriate to hold the family member accountable?*

I worry that this bill, as written, could enable government agencies to escape their responsibilities and shift them onto a responsible family member. This is especially inappropriate for responsible family members of adult consumers.

I would hope for some language to the effect that nothing in these sections shall alleviate the primary responsibility of government entities to timely deliver needed services and supports to which a disabled individual is entitled or qualifies for; additionally, this section shall not be construed to make family members who volunteer to assist a person with disabilities financially responsible for their support and maintenance in the absence of a separate agreement to assume such responsibility.

I also wonder if this bill may allow an unannounced forced inspection of a family home where a consumer lives whenever a service provider is there. The rights of others in the home are a concern.

Lastly, I believe that anonymous complaints against a family member providing uncompensated supports are inappropriate. These issues are criminal in nature. Families should have the right to know where the accusation came from.

9. AB-261 Developmental services: regional centers: suspension of services.

I support this bill. In addition to the importance of camp to people who go there, camp is typically the only available out of home respite option for many families of people with I/DD. Respite is very important to the health of family members.

Even though respite in a camp location has been authorized under the HCBS waiver for many years, it was denied by our regional center, which held that respite in a camp location was a camp benefit, regardless of the waiver. This bill will alleviate such denials.