



**LEGISLATION AND PUBLIC POLICY COMMITTEE (LPPC)
MEETING NOTICE/AGENDA**

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**THE PUBLIC MAY LISTEN IN BY CALLING:
PARTICIPANT CODE:**

**1-800-839-9416
8610332**

DATE: March 17, 2016
TIME: 1:00 p.m. to 5:00 p.m.
LOCATION: State Council on Developmental Disabilities
1507 21st Street, Suite 210
Sacramento, CA 95811
(916) 322-8481

TELECONFERENCE SITE(S):

ARC of Ventura County
5103 Walker St.
Ventura, CA 93003
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Silicon Valley-Monterey Office
2580 North First Street, Suite 240
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Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in the meeting, should contact Michael Brett at 916/322-8481 or michael.brett@scdd.ca.gov. Requests must be received by 5:00 pm on March 11, 2016.

AGENDA

PAGE

1. CALL TO ORDER

J. Lewis

2. **ESTABLISH QUORUM** J. Lewis

3. **WELCOME/INTRODUCTIONS** J. Lewis

For additional information regarding this agenda, please contact Michael Brett, 1507 21st Street, Ste. 210 Sacramento, CA 95811, (916) 322-8481.

Documents for an agenda item should be turned into SCDD no later than 12:00 p.m. the day before the meeting to give members time to review the material. The fax number is (916) 443-4957.

4. **MEMBER REPORTS** Members

This item is for committee members to provide a report on their legislative and/or public policy activities related to the agency or group they represent. Each person will be afforded up to three minutes to speak.

5. **APPROVAL OF FEBRUARY 8, 2016 MINUTES** J. Lewis 4

6. **PUBLIC COMMENTS**

*This item is for members of the public only to provide comments and/or present information to the Council on matters **not** on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first.*

7. **OLD BUSINESS (Standing Items)**

- a. Budget Update/Special Session/Lanterman Coalition B. Giovati
- b. IHSS/CMS Updates/Overtime Discussion/DC Closures C. Lapin/All 15
- c. Federal & State Legislation Updates/Council Update on LPPC Bill Package & Other Bills B. Giovati/
N. Nieblas
- d. Self-Determination J. Lewis/A. Lopez/C. Lapin/All
 - i) Update on Person Centered Planning
 - ii) Statewide SDP Committee
 - iii) HCBS
- e. Disparity Issues All 38

8. NEW BUSINESS

a. Detail Sheets/Bill Review

B. Giovati/ 46
N. Nieblas/All

- 1) AB 1553
- 2) AB 1821
- 3) AB 1824
- 4) AB 2231
- 5) AB 2383
- 6) SB 982
- 7) SB 1034
- 8) SB 1221
- 9) SB 1252
- 10) Driverless Cars

b. Press Outreach

N. Nieblas

9. ADJOURN

J. Lewis

5. APPROVAL OF FEBRUARY 8, 2016 MINUTES



DRAFT

**LPPC Committee Meeting Minutes
DATE: February 8, 2016**

Attending Members

Janelle Lewis (FA)
April Lopez (FA)
David Forderer (SA)
Sandra Aldana (SA)
Jennifer Allen (SA)
Lisa Davidson (FA)
Connie Lapin (FA)
Evelyn Abouhassan

Members Absent

Others Attending

Aaron Carruthers
Natalie Bocanegra
Bob Giovati
Michael Brett
Wayne Glusker

1. CALL TO ORDER

Chairperson Janelle Lewis (FA) called the meeting to order at 10:10 a.m.

2. ESTABLISH QUORUM

A quorum was established.

3. WELCOME/INTRODUCTIONS

Members and others introduced themselves as indicated.

4. MEMBER REPORTS

Chairperson Janelle Lewis (FA): Reported that she volunteers for the organization Families for Early Autism Treatment (FEAT) Sacramento. Families are calling regarding the transition of Behavioral Health Treatment (BHT) to Medical. These families are being cut off and pushed off to new providers.

Evelyn Abouhassan: Briefed on the following DRC 2016 Legislative Priorities:

Legend:
SA = Self-Advocate
FA = Family Advocate

- Approved their Legislative Platform in September 2015 which is on their website.
- Looking for authors on bills.
- State Council will be co-sponsoring with the DRC on AB 488.
- Would like the LPPC to consider Disability Access Bills.
- Debra Doctor is still working on IHSS/Other Budget Issues.

The committee/staff then held a discussion on Ms. Abouhassan's member report.

David Forderer (SA): Reported that Mark Stone met with Mr. Forderer in December 2015 on legislative issues.

Jennifer Allen (SA): No report.

Lisa Davidson (FA): Presented an update on vaccine bills. This is regarding the public comments given at the November 10, 2015 LPPC meeting.

Committee suggested moving this discussion to item 7c of this meeting's agenda.

Connie Lapin (FA): The following was reported on:

- Discussed a book on Autism/public policy/laws. This book came out January 19, 2016 titled *In a Different Key*. Mrs. Lapin and her husband are mentioned in Chapter 16 on the right to education. The book was then passed around for review. On February 11, 2016 there will be a book signing in LA. This book can be purchased for \$30.00 or on Amazon.com.
- Mentioned the New Day Conference that is taking place at the Autism Society of Los Angeles on February 18-19, 2016. This conference will be dealing with Self-Determination and the new HCBS rules.
- Mentioned article from the Autism Advocate.
- Mentioned Tobin World on abuse of children within the school.

- Mentioned employment settlement in Oregon. If interested in seeing this settlement, please click on the link below which is on the State Council website:

<http://www.sccd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20-%20Handout%20%202.8.16.pdf>

5. APPROVAL OF THE NOVEMBER 10, 2015 MEETING MINUTES

It was moved/seconded (Lapin)(FA), (Davidson)(SA) and carried to approve the November 10, 2015 meeting minutes with corrections. There were two abstentions from April Lopez (FA) and Evelyn Abouhassan.

(See attendance list for voting members)

Corrections made to the LPPC Packet Meeting Minutes:

- Remove last statement from Mrs. Lapin's member report located on page 5.
- On page 8 under item 7b, at the beginning of the third bullet; add many people in attendance at the DS Taskforce.
- On page 10 under 7d, first sentence; add Westside Regional Center between on and Self-Determination.
- On page 10 under 7d(ii), first bullet; remove Dr. Lopez and change to read: A letter was read that the State Council is going to convene a meeting of the chairs of the local advisory committees.

6. PUBLIC COMMENTS

There were no public comments.

7. OLD BUSINESS (Standing Items)

a. Budget Update/Special Session/Lanterman Coalition/Other Organizations

Bob Giovati, Deputy Director of Policy and Planning, briefed the committee that the Governor introduced the budget in early January 2016. Deputy Director Giovati continued to state that the Summary of

the Budget was presented to the full Council. This summary can be found on page 15 of the LPPC Packet.

To view this summary, please click on the below link which located on the SCDD Website:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%202.8.16.pdf>

The following was discussed with the committee concerning the budget:

- The Governor's Office would like the I/IDD community to specify targeted issue areas they want funding to go to.
- Governor does not like across the board increases. Need to come together as a community.
- Governor wants groups to come to the table on what monies are needed and where it needs to go.
- Discussed the Lanterman Coalition regarding the 10%.
- Mrs. Lapin (FA) mentioned the organization, California Person Centered Advocacy Partners. The committee then held conversation regarding this issue. This was a handout that was passed out to the committee. This handout can be viewed by clicking on the below link which is located on the SCDD Website:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%202.8.16.pdf>

- Mentioned to the committee that the State Plan is measuring outcomes.
- Discussed creating pilot program with legislation measures.
- Discussed the Coming Together (People) Meeting taking place in Sacramento on March 2, 2016. Times to be determined.

b. IHSS/CMS Updates/Overtime Discussion

Chairperson Lewis (FA) briefed the committee that different organizations are confusing families regarding these rules. Most of the confusion is how the rules apply to certain situations. These overtime rules began February 1, 2016.

Mrs. Lapin (FA) explained how these changes are affecting families. She also explained that our legislature needs to know the hardship these rules are causing families/self advocates.

Ms. Abouhassan offered to have Debra Doctor explain these IHSS updates/overtime by holding a possible teleconference with the committee.

Chairperson Lewis (FA) also stated that the State Council Regional Offices need to have an understanding of these rules.

As of January 25, 2016, the DRC has the most current information about In-Home Supportive Services (IHSS) Overtime and Related Changes. Debra Doctor also has a PowerPoint Presentation. These updates/presentation can be found on the DRC website. The link to this website is located below:

<http://www.disabilityrightsca.org/Events/20150IHSSOvertimeInformation.htm>

Dr. Sandra Aldana suggested that she would contact the Tri County Regional Center regarding training materials. This could help the Council start a monitoring process. Committee is in agreement to this.

c. Federal and State Legislation Updates/Council Update on LPPC Bill Package and Other Bills.

During the last LPPC meeting, the committee came up with a number of ideas for potential bills. Since then, these ideas were presented/approved by the full Council.

Deputy Director Giovati briefed the committee that these ideas came from various sources. Currently, staff is looking for legislators to author these bills. Staff has also been working with potential authors.

New bills are coming in for the second half of this two year session. Staff is watching them for potential interest.

During this meeting, staff also presented some federal bills to the LPPC. Staff then asked the committee if they would like the bills presented to the full Council.

These are the items presented to the committee:

SCR 98: For this particular resolution, staff/committee felt that this bill should be fast tracked to the Executive Committee meeting (being held February 9, 2016) instead of waiting for the March 8, 2016 Council Meeting. Committee agreed to the following motion:

It was moved/seconded (Lapin)(FA), (Forderer)(SA) to have the Executive Committee approve the support position of the SCR 98 bill. There were no abstentions. All are in favor.

(See attendance list for voting members)

To see the full description of the bill, please click on the below link:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%202.8.16.pdf>

AB 1565: Staff (FA) gave a briefing on this bill and then the committee held a discussion. It was decided by the committee to watch this bill with the following motion:

It was moved/seconded (Forderer)(SA), (Davidson)(FA) to watch AB 1565 for more clarity. Committee wants to send a clear message to the author that it likes the bill and is willing to help. There were no abstentions. All are in favor.

(See attendance list for voting members)

The full description of this bill can be found in the LPPC Packet on page 25. Please click on the below link which is located on the SCDD Website:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%202.8.16.pdf>

S 1719: Staff gave a briefing on this bill and then the committee held a discussion. It was decided by the committee to present this bill to the full Council with the following motion:

It was moved/seconded (Forderer)(SA), (Lapin)(FA) to have the full Council approve the support position of the S 1719 with one abstention from Evelyn Abouhassan.

(No vote recorded for Dr. Aldana (SA). See attendance list for other voting members)

The full description of this bill can be found in the LPPC Packet on page 30. Please click on the below link which is located on the SCDD Website:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%202.8.16.pdf>

S 2427: Staff gave a briefing on this bill and then the committee held a discussion. It was decided to watch this bill with the following motion:

It was moved/seconded (Forderer)(SA), (Lopez)(FA) to watch S 2427 with two abstentions from Lisa Davidson (FA) and Evelyn Abouhassan.

(No vote recorded for Dr. Aldana (SA). See attendance list for other voting members)

The full description of this bill can be found in the LPPC Packet on page 39. Please click on the below link which is located on the SCDD Website:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2016/LPPC%20Packet%202.8.16.pdf>

Staff then briefed the committee that the Council is currently watching 80 to 90 bills thus far for 2016.

Staff also mentioned that prior to convening of this LPPC Meeting, staff went to the Capitol and met with the following offices: Senators: Kevin de Leon and Holly J. Mitchell and Assembly members: Anthony Rendon and Tony Thurmond. This was to introduce them on the workings of the State Council and to let the Senators/Assembly members know that our Executive Director and Chair of the Council would like to meet with them.

AB 277: Committee discussed this vaccine bill regarding its amendment/Special Education issues.

d. **Self-Determination**

The State Council will be holding a reception after the Self-Determination Conference for the Chairs of the Self-

Determination/participants. This takes place Thursday evening, February 18, 2016. For more details, see item 4 of these minutes on Mrs. Lapin's (FA) member report on the New Day Conference.

Mrs. Lapin (FA) briefed the committee that the waiver has been submitted. She also discussed the following concerns:

- CMS came back with questions.
- LA Regional Advisory Committee mentioned FMS charges.
- Mrs. Lapin (FA) will be attending the Self-Determination Workgroup on February 10, 2016.
- Self-Determination is a huge cost.
- Some Local Advisory Committees do not have enough information.

i. Update on Person Centered Planning

The committee held a discussion on Person Centered Planning.

ii. Statewide SDP Committee

The Statewide Self-Determination Advisory Committee is taking place March 3, 2015 at the Westside Regional Center (Boardroom) in Los Angeles from 10:00 a.m. to 5:00 p.m. The public will be able to attend this meeting. The Council is only paying for Chairs of the committee to attend.

e. Disparity Issues

Aaron Carruthers, Executive Director, recapped the committee on disparity issues from the last meeting conducted February 8, 2016. He continued to state the concerns of the statutes and the role the Council plays on disparity. He also discussed what the Council can do regarding POS Data/Reports/Meeting best practices.

Executive Director Carruthers also discussed the following:

- Demographic catchment areas vs. regional center service population gaps.

- ARCA has invited the State Council and the DRC to be on their Equity Committee. Catherine Blakemore, DRC and Executive Carruthers attended this meeting.
- Council is spearheading a style guide which will be translated into different languages.

The committee then held more discussions on disparity and mentioned the following:

- Individual rights, 45 day period, and threshold languages.
- Council is incorporating training for families to be their own advocates.
- Requirements for IPPs.

8. NEW BUSINESS

a. Bagley-Keene Questions

The committee asked Natalie Bocanegra, SCDD legal counsel, to answer questions on what can/can't be done with Bagley-Keene. Ms. Bocanegra discussed the following points:

- Bagley-Keene applies with state entities.
- Open meeting goals are so the public knows what is being done within a committee.
- Meeting concepts are when a certain number of people get together in a committee (state body) to deliberate, talk, and exchange information.
- Bagley-Keene applies when a state body represents the public's business/interests.
- Explanation of a Quorum:
 - A quorum must be present to share information during a meeting. A quorum consists of 50 percent plus one committee member.
- Other areas of interest:
 - Two or less members are not considered a meeting. However, three or more is considered a meeting.
 - Meeting must be announced in order for it to take place.
 - Public comments do not act on agenda items. It allows members of the public to discuss items that are not on the agenda.

- Serial meetings may cause a meeting outside the announced meeting.
- It is a best practice to discuss any information to more than one committee member in an official announced committee meeting.
- Discussed different scenarios of exchanging information outside an official meeting.
- One important point, in most cases, staff can receive information from each member and then relay it to all committee members in an official announced meeting.

b. State Plan Goals/Legislative Priorities 2016

Chairperson Lewis (FA) briefed the LPPC on how the State Plan Committee (SPC) has been working on the DRAFT 2017-21 State Plan. Chairperson Lewis (FA) also discussed what has been accomplished during this process:

- Plan consists of 6 goals which have 3 to 4 objectives under each goal.
- AAIDD, our federal partners, asked the State Council to cut down the goals for this State Plan.
- Federal Areas of Emphasis.
- Work Plan goes over how the objectives are implemented throughout the State Council.
- The 6 goals are as follows:
 - Employment.
 - Housing.
 - Health and Safety.
 - Early Intervention and Education.
 - Formal and Informal Community Supports.
 - Self Advocacy.
- 45 Day public input period.

- Plan will go final in August 2016.

The committee then held a discussion on the DRAFT State Plan.

c. Council Strategy at Capitol

The committee discussed how the LPPC presents and testifies on bills at the Capitol. A conversation ensued as to whether there was a more practical and expeditious way for the Council to delegate some added legislative authority to the LPPC and staff.

Please refer to item 7c of these minutes for additional items on staff's strategy at the Capitol.

d. 2016 LPPC Meetings/SCDD Structural Deficit

- Chairperson Lewis (FA) discussed with the committee how important issues/bills can be taken care of before Council Meetings. It was determined that these matters need to go through the proper channels for approval.
- Discussed the approved Legislative Platform/State Plan that guides this committee.
- It was discussed to meet six times a year. If meetings need to occur, between meetings can be scheduled.
- Next meeting may take place March 14, 2016. Additional meeting dates will be discussed at the next LPPC meeting.

e. Press Outreach

This item was not discussed.

9. ADJOURN

Meeting adjourned at 3:26 p.m.

**7b. IHSS/CMS
UPDATES/OVERTIME
DISCUSSION/DC CLOSURES**



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Joint Hearing
Senate Human Services Committee
Senate Budget and Fiscal Review Subcommittee No. 3 on Health and
Human Services
Tuesday, February 23, 2016
1:30 p.m.
State Capitol, Room 4203

**A Defining Moment: Considering the Closure of Developmental Centers
and Its Impact on Residents, Families, and the Regional Center System**

**Testimony Regarding Maintaining a Safety Net: What Should Be the State's
Ongoing Role in Providing Unique Services, Addressing Unmet Needs, and
Ensuring the Well-Being of Those with Challenging Medical and Behavioral
Needs**

Testimony of Catherine Blakemore, Executive Director

Disability Rights California is the federally mandated protection and advocacy system and works to advance dignity, equality, independence, and freedom of Californians with disabilities. In addition to our federally required services, we provide the clients' rights advocacy assistance for consumers and their families at the 21 regional centers. Last year, we provided advocacy assistance to 25,736 individuals with disabilities including individuals with intellectual or developmental disabilities. In addition, through more than 800 trainings we provided more than 40,000 individuals with disabilities and their families with information about their rights. Our systemic and policy advocacy positively impacted more than 500,000 individuals.

The developmental disabilities system is in transition driven by a number of factors including the proposed closure of state developmental centers;

service complexities which contribute to unmet need; and new federal Medicaid and overtime requirements. We welcome this opportunity to provide our perspective on the critical steps the state must take to strengthen the service system and meet the unique and unmet service needs of each regional center consumer.

Creating a Strong Community Safety Net

With the closure of Sonoma, Fairview, and the non-forensic units at Porterville Developmental Centers, the community will be the safety net for the nearly 290,000 regional center consumers. We know first-hand the importance of adequate crisis and new service models for regional center consumers.

Last year we assisted Tyler. When Tyler's family could no longer provide the care she needed because she was having seizures, she was placed in a nursing facility and then a hospital. While her physical health improved, the extended hospital stay was stressful, and she experienced significant behavioral challenges. The regional center was not able to locate an appropriate living arrangement, and the community hospital didn't know how to handle her behavioral challenges so they restrained her in an enclosed bed. Being confined affected her speech and mobility, and her physical and mental health. Because there was not adequate community crisis capacity to address her behavioral challenges, our clients' rights advocate worked with the regional center and department to place her temporarily in the State's short-term acute crisis unit at a developmental center, and our Investigations Unit educated the hospital about their inappropriate use of seclusion and restraint. After a few short months Tyler's behavior, ability to express herself and her social skills greatly improved. She is now deciding where she wants to live in the community.

To ensure a strong community safety net, we encourage the State to do the following:

1. Work with the regional centers to expeditiously develop the quality enhanced behavioral health support homes required by statute. We are pleased that last month the Department submitted regulations that will allow these homes to become operational, but note that the Department of Social Services companion regulations, which address critical elements such as emergency behavior plans, the use of restraint and monitoring of behavioral services, have not been developed.

2. Promptly develop increased crisis capacity. The Department has yet to complete the development of regulations for crisis homes services or to expand access to crisis services provided in an individual's current home. Without this increased crisis capacity, we are concerned that inappropriate and expensive models such as locked institutions for mental disease (IMDs) will remain a common way of providing short and long-term crisis services. We have concerns about the cost of these services, since, for many individuals, the service is ineligible for Medi-Cal funding due to an exclusion in federal law; and more importantly, about the quality of service.
3. Develop "placements of last resort" as called for in the DC Task Force Report and work with stakeholders to determine the most effective means of providing these services including the State's on-going role in providing these services.

Currently, the State operates small, short-term acute crisis units at Sonoma and Fairview. These programs have been successful due to clear statutory requirements requiring immediate and ongoing assessment of the individuals need and one year time-limited placements as well as the involvement of clients' rights advocates in the process, and the department's willingness to intervene with licensing and other agencies to ensure new living arrangement can timely open. WIC 4418.7(e)

The community will not be able to be the safety net without similar capacity and requirements regarding the use of such facilities. At a minimum, the Department must have dedicated staff to ensure ongoing state involvement in these placements. Because private providers can also decline to serve individuals, we believe that State should have a role in providing residential services to those whom the private sector cannot serve; either with small state owned and operated facilities, or state supports in privately operated facilities.

4. Modify Health and Safety Exception Process. Exceptions to rate freezes and median rates are available for people whose service needs necessitate a higher rate. This is possible on an individual basis only by applying for a Health and Safety Waiver. In practice this is a lengthy process, requiring approval from both the regional center executive director and DDS. This process must move faster. Consideration should also be given to allowing regional enters to approve rate exceptions when exceptional circumstances exist.

5. Ensure adequate oversight of facilities providing short and long-term services to individuals in crisis including increased access to information and records by Disability Rights California, the federally mandated protection and advocacy agency.

One of Disability Rights California's most important responsibilities is the investigation of abuse and neglect including the use of restraints in facilities providing care and treatment. DRC's Investigation Unit has been investigating cases of alleged abuse and/or neglect of residents at one IMD where regional center consumers are placed. Because of the gravity of our concerns, we filed complaints with the federal and state agencies. The Center for Medicaid and Medicare (CMS) made an unannounced site visit and due to flagrant health and safety violations, including failure to investigate two sexual assault complaints, made a finding of "Immediate Jeopardy." While the facility remedied the immediate concerns, our monitor continues to document problems with ongoing abuse, injury, inappropriate use of restraints and the death of a resident.

Several years ago when there were concerns about the quality of care at state developmental centers, state law was changed to require increased reporting to DRC about specific types of injuries suggestive of abuse or neglect. With the transition to a community safety net, we propose that state law is amended to require that the protection and advocacy agency receive similar reports of injuries from IMDs, community crisis facilities and enhanced behavioral support homes. (See attached)

Also, we encourage reduced caseloads for individuals who are receiving crisis services and are placed in community institutions such as locked IMDs. These individuals are likely to be the same individuals who would have been placed at developmental centers. Current law requires a reduced case load for individuals who are moving from developmental centers to the community this have been an important element for their successful transition, and we encourage a similar approach for individuals who are in crisis or locked facilities in the community.

Reduce Service Complexities

Beginning in 2009, due to the economic crisis, the State made more than a billion dollars in cuts to the developmental disabilities system. We are grateful for the efforts to restore funding for providers and regional centers

through the Managed Care Organization (MCO) tax proposals, and the efforts to improve outcomes in the employment area. However, an unintended consequence of the reductions is the increased complexity of the service system, which makes it difficult for consumers and families to access the services they need, and in the end, does not result in real savings to the State as the services are Medicaid funded, regardless of which state agency provides them.

In addition, the recent changes in federal law require the payment of overtime to workers providing personal care services. As a result, some service providers, have eliminated all overtime expenditures, others have required parents and conservators to sign agreements obligating the parent and consumer to assume full responsibility for managing the IHSS services even when a consumer is placed in a home operated by the provider. At least one regional center has sent a letter to all clients and families instructing them not to ask workers or caregivers to work extra hours as the rates paid to service providers do not allow for overtime pay, even though the Legislature approved a 5.82% rate increase expressly for this purpose. For consumers with the most significant needs, they often need continuity of support and support provided by a more highly trained worker. This often is not possible with IHSS due to high turnover.

Similar problems arise when individuals need to access medical or dental services provided through Medi-Cal. During the economic crisis, the law was changed to prohibit a regional center from purchasing medical or dental services for a consumer three years of age or older unless the regional center is provided with documentation of a Medi-Cal, private insurance, or a health care service plan denial, and the regional center determines that an appeal by the consumer or family of the denial does not have merit. Regional centers may pay for medical or dental services pending a final administrative decision on the administrative appeal if the family provides verification that an appeal is being pursued. The result is that families are required to appeal any decisions denying their child access to critical occupational or physical therapy, speech and language services, or dental services before regional centers will agree to pay for the service. This happens even though the State will should not save any money since the services are Medicaid eligible regardless which agency provides the services. The unintended consequence is that low-income families that use Medi-Cal do not have the time, resources or skills to appeal an adverse Medi-Cal decision and thus forego the service—which results in savings to the State.

As a way of reducing some of this complexity, we encourage you to do the following:

1. Change §WIC 4689 (f) to allow consumers' IPP teams to determine if using IHSS is an appropriate generic service. In making this determination, the IPP Team would consider the following: the nature or extent of the consumer's disability, the need for staff continuity and the need for supportive services staff with a higher level of skill, training or expertise. If the planning team determines that IHSS services are not appropriate, the consumer would not be required to utilize those services. (See attached WIC §4689(f) revision)
2. Make statutory changes clarifying that regional center funded home care services (Supported Living Services (SLS), In-Home Respite and Personal Assistance Centers) are not joint employers with IHSS or Waiver Personal Care Services.
3. Provide funding for pilot programs that provide access to temporary workers who can provide services when either the IHSS worker has exceeded the state-imposed overtime limits or the provider will not authorize overtime.
4. Ensure that the current state overtime provisions that allow a worker to work up to 66 or 70.5 hours apply to the regional center system including a funding allocation to specifically target this overtime. For example, when an SLS worker working for one SLS agency is paid through both IHSS and regional center funds, that worker should be eligible to work up to 66 or 70.5 hours per week regardless of the funding source. In addition, the statute should allow the same additional exceptions to these limits as is allowed in the IHSS program.
5. Amend WIC Section 4659 to no longer require families to pursue Medi-Cal administrative hearings before regional centers can pay for medical and dental services available through the Medi-Cal program. (See attached)
6. Provide additional Service Coordinators who can help families navigate generic services.

Improve Access to Mental Health and Dental Services

Dental Services

Children and adults with disabilities experience significant barriers to obtaining needed dental services as a result of low Denti-Cal reimbursement rates; this is related to the shortage of qualified providers, and the lack of adequate reimbursement for disability-related appropriate procedures and methods.

Denti-Cal rates are generally far lower than rates for private insurance. See page 32 of the State Auditor's report on Denti-Cal for children, available at <https://www.auditor.ca.gov/pdfs/reports/2013-125.pdf>. Likewise, anesthesia rates for Denti-Cal are significantly lower than rates for private insurance. For example, a typical private insurance rate is \$275 for the first 30 minutes of anesthesia and \$100 for each additional 15 minutes. On the other hand, a typical Medi-Cal rate is \$42.14 for the first 30 minutes and \$21.07 for each subsequent 15 minutes.

For people with disabilities, such as those with autism who may have difficulty communicating symptoms associated with dental problems or have behavioral challenges that make routine dental care more difficult to provide, the access problems are compounded particularly when specialized services are not available or the rates for those services are too low. When treatment is not available, individuals too often develop serious infections or horrendous pain and have no choice but to go to hospital emergency rooms, where they receive very expensive symptomatic care. For individuals with developmental disabilities, regional centers are "payers of last resort" for the disability-related services that their clients need. This means that regional center consumers must access generic services, such as Denti-Cal, before the regional centers can pay for the service. The requirement of requesting generic Denti-Cal services exists even when it is known that the service rate or type of service is inadequate given the disability-related needs and as a result, many months will have elapsed between the initial request for the service and when the service is provided.

As part of the Agnews Developmental Center closure plan, some regional centers received funding for Dental Coordinators to help ensure that consumers leaving Agnews could continue to access appropriate dental care. The use of Dental Coordinators proves to be an effective means of ensuring access to dental services. Some regional centers continue to have Dental Coordinators, and it appears that access to dental services is

enhanced at those regional centers. The Agnews and Lanterman closure plans continued the availability of dental services at those developmental centers.

We recommend the following solutions:

1. **Funding for Regional Center Dental Coordinators** at each regional center, as this is a proven way to increase access to dental services either by assisting consumers and families in accessing Denti-Cal or by quickly determining that Denti-Cal cannot provide appropriate specialized dental services and use purchase of service funds to obtain the needed services.
2. **Increase the rates for anesthesia dental care and the rates for common preventive dental care.** Consistent with the State Audit and other available information, California's Denti-Cal rates are extremely low compared to other states, inhibiting access to care and permit Denti-Cal reimbursement for services such as scaling and root cleaning, and periodic comprehensive evaluations. Increase the dental anesthesia rate to provide rate parity between anesthesia for other services and anesthesia for dental services.
3. **Some developmental center dentists and staff have specialized expertise regarding the unique dental needs of regional center clients.** Through the closure process, it is important to ensure that dental services and staff expertise regarding provisions of dental services continues to be available in the community.

Mental Health Services

As noted in the DC Task Force Report, an overarching issue is access to mental health services including care coordination and appropriate and continuous medication management. The Task Force Report notes that 22% of individuals living in Developmental Centers have prevailing psychiatric/mental health issues, and 51% are prescribed at least one psychiatric medication targeting behavioral challenges. From our work with individuals dually diagnosed with mental health and developmental disabilities who live in the community, we also know that these individuals are often served in emergency rooms and local hospitals, and have great difficulty accessing community mental health services.

We recommend that the Department convene stakeholders to look at current effective models of providing access to mental health services and new and innovative options that can be attached to the yet to be developed community crisis services.

Obtain Federal Approval and Implement the Self-Determination Program

In 2013, the Legislature unanimously approved, and the Governor signed into law, SB 468 which created a statewide Self-Determination Program; a voluntary, alternative to the traditional way of providing regional center services. It provides consumers and their family with more control over the services and supports they need. Self-determination provides consumers, and their families, with an individual budget, which they can use to purchase the services and supports they need to implement their Individual Program Plan (IPP). Consumers and families may for example, purchase existing services from services providers or local businesses, hire support workers, or negotiate unique arrangements with local community resources. Family members of individuals residing at State Developmental Centers have indicated that this is one of their preferred ways to provide services as their loved one transitions from the developmental center to the community.

While the Department and regional centers have taken important steps to implement the program, we have yet to receive federal CMS approval due in large part to the inter-relationship between this waiver and the required Home and Community Based Services regulations required Transition Plan. The Transition Plan and the Self-Determination Waiver must both demonstrate how the State will ensure that as of March 2019, all waiver services, including self-determination services, meet the federal integration and choice requirements.

We encourage the Department to continue, and expedite, its work with Stakeholders to develop a strategy that provides sufficient assurances to CMS that the Self-Determination Waiver meets the HCBS requirements and if necessary, obtain a conditional time-limited approval. The experience of the Self-Determination Pilot Program is that consumers and families experience a high level of satisfaction with this program and that the cost to the state is often less than the costs associated with the traditional regional center service system.

Statutory Changes

Monitoring of Facilities and Living Arrangements Serving Individuals with Developmental Disabilities

Amend Welfare and Institutions Code 4659.2

(b) All regional center vendors that provide crisis or residential services or supported living services, long-term health care facilities, and acute psychiatric hospitals shall report the following to the agency designated pursuant to subdivision (i) of Section 4900 the following:

(1) Each death or serious injury of a person occurring during, or related to, the use of seclusion, physical restraint, or chemical restraint, or any combination thereof

(2) Any unexpected or suspicious death, regardless of whether the cause is immediately known.

(3) Any allegation of sexual assault, as defined in Section 15610.63, in which the alleged perpetrator is a staff member, service provider or facility employee or contractor.

(4) Any report made to the local law enforcement agency in the jurisdiction in which the facility is located that involves physical abuse, as defined in Section 15610.63, in which a staff member, service provider or facility employee or contractor is implicated.

~~(start delete) to the agency designated pursuant to subdivision (i) of Section 4900 (end delete)~~

(5) The reports required in Sections (1)-(4) shall be made no later than the close of the business day following the following the death or serious injury. The report shall include the encrypted identifier of the person involved, and the name, street address, and telephone number of the facility.

(c) On a monthly basis all regional center vendors that provide residential services or supported living services, long-term health care facilities, and acute psychiatric hospitals shall report the following to the agency designated pursuant to subdivision (i) of Section 4900 the following:

(1) The number of incidents of seclusion and the duration of time spent per incident in seclusion;

(2) The number of incidents of the use of behavioral restraints and the duration of time spent per incident of restraint; and

(3) The number of times an involuntary emergency medication is used to control behavior.

(4) The reports required in sections (1)-(3) shall include the name, street address and telephone number of the facility.

Amendments to Ensure Access to Personal Care Services for Individuals Living in Supported Living Arrangements.

Amend WIC 4689

(f) The planning team, established pursuant to subdivision (j) of Section 4512, for a consumer receiving supported living services shall confirm that all appropriate and available sources of natural and generic supports have been utilized to the fullest extent possible for that consumer. The consumer's individual program planning team shall review and determine if the supportive services provided by the IHSS program are appropriate to meet the consumer's needs. In making that determination the individual program planning team shall consider the nature or extent of the consumer's disability, the need for staff continuity and the need for supportive services staff with a higher level of skill, training or expertise. If the planning team determines that IHSS services are not appropriate, the consumer shall not be required to utilize those services notwithstanding the requirements of sections 4659 and 4689.05.

Amendments to Ensure Access to Appropriate Medical or Dental Care without the Necessity of Pursuing a Medi-Cal Appeal

Amend to WIC Section 4659(d)

(d) (1) Effective July 1, 2009, notwithstanding any other law or regulation, a regional center shall not purchase medical or dental services for a consumer three years of age or older unless the regional center is provided with documentation of a Medi-Cal, private insurance, or a health care service plan denial (start delete) and the regional center determines that an appeal by the consumer or family of the denial does not have merit. ~~If, on July 1, 2009, a regional center is purchasing the service as part of a consumer's IPP, this provision shall take effect on August 1, 2009 (end delete).~~ Regional centers may pay for medical or dental services during the following periods:

(A) While coverage is being pursued, but before a denial is made.

(Start delete) ~~(B) Pending a final administrative decision on the administrative appeal if the family has provided to the regional center a verification that an administrative appeal is being pursued. (end delete)~~

(C) Until the commencement of services by Medi-Cal, private insurance, or a health care service plan.

(2) When necessary, the consumer or family may receive assistance from the regional center, the Clients' Rights Advocate funded by the department, or the state council in pursuing these (start delete) appeals (end delete) denials.



IHSS Coalition

QUALITY CARE BEGINS AT HOME

February 29, 2016

The Honorable Tony Thurmond, Chair
Assembly Budget Subcommittee #1
State Capitol
Sacramento, CA 95814

The Honorable Holly Mitchell, Chair
Senate Budget Subcommittee #3
State Capitol
Sacramento, CA 95814

RE: Request to Restore the IHSS Share-of-Cost Buy-Out

Dear Assembly Member Thurmond and Senator Mitchell;

The IHSS Coalition is composed of forty-eight organizationsⁱ representing IHSS consumers, providers and advocates. Our goals are (1) to ensure sufficient funding for In-Home Supportive Services and its interrelated aspects (2) to develop potential improvements for the program, (3) to disseminate information on homecare issues through public events and our website, and (4) to preserve and enhance consumer-directed services.

We write to request the restoration of the IHSS Share of Cost Buy-out.

The 2009 repeal of the IHSS share of cost buy-out left some IHSS consumers, who have income **above** the SSI amount (currently \$889.40 for an individual) with substantially **less** than the inadequate SSI level income to live on. To receive IHSS, they must spend down to **\$600** the Medically Needy amount.

Having only \$600 to live on leaves these consumers at more risk for

institutionalization, and makes it more difficult if not impossible for some people to leave nursing homes, faced with the prospect of living on \$600 a month.

Background:

What is a Share of Cost (SOC)

Share of cost is like an insurance premium deduction. An IHSS consumer with a SOC is responsible for paying the provider the share of cost first. Once the SOC is met, IHSS will pay the provider for the remaining services.

Most IHSS consumers qualify financially for Medi-Cal and IHSS because they are on SSI. Those consumers do not have to pay a SOC. Some consumers with income higher than SSI may qualify for Medi-Cal and IHSS through other programs, without a share of cost or with a share of cost which brings their income to the SSI level. However, an individual IHSS consumer with a countable income above \$1,211, who does not qualify for one of the other programs, must pay a \$612 share of cost which leaves the consumer with only \$600 a month to live on – the Medically Needy Income Level. This means that some seniors and people with disabilities with a modest Social Security or private retirement benefit end up with less than someone who depends on SSI.

Example: If an IHSS consumer has SSI of \$889.40, no share of cost is required. If an IHSS consumer has countable monthly income of \$1,300, that consumer must pay \$700 towards IHSS services and other medical needs, leaving \$600 to meet all housing and food and other expenses.

What was the Share of Cost buy-out?

Before the late 1990's, IHSS was not part of the federal Medicaid program. People who paid a share of cost to get IHSS paid down to the SSI level. In 1998, the disability community supported drawing down federal Medicaid dollars into the IHSS program in part because the state government promised that IHSS recipients would not be penalized by the result. That is, IHSS consumers would still pay a share of cost down to the SSI level rather than having to pay a much larger share of cost to qualify for IHSS because it became a Medi-Cal program.

To keep the promise and hold consumers harmless, the state paid – or “bought out” – the difference between the higher Medi-Cal share of cost and the lower IHSS SOC so that the transfer to federal funding – which now pays around half of

the cost of IHSS - would not penalize recipients who prior to Medi-Cal covering IHSS spent down to the SSI grant level. The advantage of an enormous influx of federal money was well worth the relatively insignificant cost of the Buy-out.

Example: For example, for a recipient with an IHSS SOC of \$200 and a Medi-Cal SOC of \$500 per month, the state would pay the difference between the IHSS SOC and the Medi-Cal SOC (\$300) while the recipient would be obligated to meet the lower IHSS SOC (\$200).

What happened to the SOC Buy-out?

As part of the 2009–10 budget, the IHSS SOC Buy-Out program was eliminated. The bills that eliminated the SOC buy-out were SBX3 6 and ABX4 4 from 2009.

IHSS recipients with a share of cost now have to meet the higher Medi-Cal SOC before the IHSS program pays for the remaining costs of their services.

How much did the state save by eliminating the SOC buy-out?

Estimates vary widely; we don't know. We don't know how many people would qualify now for it.

What happened to the buy-out money?

The buy-out money went into the Health Care Deposit Fund.

The reports show the Health Care Deposit Fund had the following end-of-year balances:

- 2007 = 15,179,000
- 2008 = 13,725,000
- 2009 = 13,616,000
- 2010 = 11,805,000
- 2011 = 1,166,000

There isn't any description of the purpose of the account in these reports.

We urge you to ask:

1. Why was there any money in the fund in 2011 and what happened to it?

2. Why was there so much left in 2010 when the buy-out ended in 2009?
3. What happened to that \$11,805,000 after 7/1/2010?
4. What were the expenditures from the fund every year?

Conclusion: Some low-income IHSS consumers, who have incomes above SSI, are being forced to live on \$600 a month, which is less than the SSI level. It is time to reinstate the IHSS Share of Cost Buy-out so IHSS consumers can retain the SSI level income of \$889.40, meet their share of cost, receive IHSS services and remain safely in their homes.

Sincerely,

AARP-California

Access to Independence

ACLU of Southern California

Alzheimer's Association, California Council

Bet Tzedek Legal Services

California Alliance for Retired Americans (CARA)

California Association of Public Authorities (CAPA)

California Church IMPACT

California Council of Churches

California Council of the Alzheimer's Association

California Council of the Blind

California Disability Community Action network (CDCAN)

California Foundation for Independent Living (CFILC)

California IHSS Consumer Alliance (CICA)

California Senior Legislature

Californians for Disability Rights, Inc. (CDR)

Communities Actively Living Independent & Free (CALIF)

Congress of California Seniors (CCS)
Dayle McIntosh Center for the Disabled
Disability Rights California (DRC)
East Bay Community Law Center
Educate.Advocate
FREED Center for Independent Living
Friends Committee on Legislation
Gray Panthers
IN SPIRIT
Independent Living Resource Center Inc.
Independent Living Services of Northern California (ILSNC)
Justice in Aging (formerly the National Senior Citizens Law Center)
Marin IHSS Public Authority
Nevada-Sierra-Plumas Public Authority
Northern California ADAPT
Older Women's League
Personal Assistance Services Council of Los Angeles
Resources for Independent Living
San Francisco IHSS Task Force
San Francisco Public Authority
SEIU Local 2015
Senior & Disability Action (SDA)
Service Employees International Union – State Council
Silicon Valley Independent Living Center (SVILC)
Southeast Asia Resource Action Center | California Office
The Arc and United Cerebral Palsy in California

The San Diego IHSS Coalition
Tri-County Independent Living Center, Inc.
UDW /AFSCME Local 3930
Westside Center For Independent Living (WCIL)

cc: Members, Assembly Budget Subcommittee #1
Members, Senate Budget Subcommittee #3
Jennifer Troia, Office of the Senate President Pro Tem
Gail Gronert, Office of the Assembly Speaker
Nicole Vasquez, Deputy Chief Consultant, Assembly Budget
Theresa Pena, Consultant, Senate Budget Committee
Chantelle Denny, Senate Republican Fiscal Office
Cindy Hillery, Assembly Republican Caucus
Matt Paulin, Program Budget Manager, HHS, Department of Finance
Will Lightbourne, Director, California Department of Social Services
Michael Wilkening, Health and Human Services Agency
Ginni Bella, Legislative Analyst's Office
Callie Freitag, Legislative Analyst's Office

¹ One organization was unable to sign on to this letter: California State Council on Developmental Disabilities requires approval from the SCDD Legislative Public Policy Committee (LPPC). Their committee meeting that is not scheduled to until after the deadline of the letter.



IHSS Coalition

QUALITY CARE BEGINS AT HOME

March 2, 2016

The Honorable Tony Thurmond, Chair
Assembly Budget Subcommittee #1
State Capitol
Sacramento, CA 95814

The Honorable Holly Mitchell, Chair
Senate Budget Subcommittee #3
State Capitol
Sacramento, CA 95814

RE: IHSS Budget: 7% Across-the-Board Cut

Dear Assembly Member Thurmond and Senator Mitchell;

The In-Home Supportive Services (IHSS) Coalition supports the Governor's budget proposal to restore IHSS service hours that were eliminated as a result of 7 percent across-the-board cut enacted in 2013 and respectfully urges a permanent repeal of this cut. The IHSS Coalition is composed of fifty organizations representing IHSS consumers, providers and advocates. Our goals are (1) to ensure sufficient funding for In-Home Supportive Services and its interrelated aspects (2) to develop potential improvements for the program, (3) to disseminate information on homecare issues through public events and our website, and (4) to preserve and enhance consumer-directed services.

IHSS keeps Californians with disabilities, including seniors, in their own homes and saves taxpayers hundreds of millions of dollars in doing so. The IHSS program provides personal care and domestic services to

approximately 490,000 individuals who are aged, blind or have disabilities, which allow these individuals to live safely at home rather than in unnecessary, not desired and more expensive out-of-home placement facilities. IHSS is a critical component of long-term care services in California.

By definition, IHSS consumers are very poor; the vast majority have monthly incomes less than \$1,000 and \$2,000 in personal assets. According to the California Department of Social Services (CDSS), approximately 85% of all IHSS consumers receive SSI/SSP. The FY 15/16 maximum monthly SSI/SSP grant for elderly and disabled individuals is \$889 per month and the maximum grant for couples is \$1,496. The average IHSS consumer is projected to receive 102 hours of service a month in FY 16/17.

7% Across-The-Board Cut

In 2013 the legislature adopted the provisions of a settlement agreement to resolve two class-action lawsuits related to IHSS cuts that were previously enacted: *Oster v. Lightbourne* and *Dominguez v. Schwarzenegger*. The cuts that were subject to these lawsuits were enacted when the state was dealing with significant budget deficits and, if implemented, the reductions would have been devastating to IHSS consumers and providers.

The settlement agreement and related implementing legislation repealed those reductions and established an 8% across-the-board cut that took effect on July 1, 2013. Under current law, the 8% cut was replaced with a 7% across-the-board cut on July 1, 2014. The settlement agreement also included a provision to “trigger off” the ongoing 7% reduction—in whole or in part—if the state receives enhanced federal funding pursuant to an “assessment” (likely a fee or tax) on home care services, including IHSS.

The 7% across-the-board cut hurt IHSS consumers and providers when it was placed into effect. A consumer assessed as needing the average number of monthly hours lost 6 of those hours – time which was needed for laundry or bathing or grocery shopping. A consumer who is assessed as needing the maximum number of hours – 283 – lost 20 hours of help per month – more than two days of personal care or domestic services. The

need didn't go away – but the help did.

Consumers have suffered disproportionately in recent years, with the IHSS hours cut compounded by cuts to SSI/SSP and Medi-Cal services, which are not proposed for restoration in the proposed budget.

In 2015-16, the service hours were restored through the use of the General Fund on a one-time basis, with the intent that an alternative funding source would be used in future years. During the recent debate and subsequent action by the legislature on the Managed Care Organization tax, the administration conveyed their intent to restore the 7% cut with state General Funds.

Closing Comments:

This year, we need all of you to do what you know is right – and what you've done before: Stand up for the California consumers of IHSS, their families and the workers who provide their much-needed care. We call on you to permanently repeal the 7% across-the-board cuts.

Sincerely,

AARP-California

Access to Independence

ACLU of Southern California

Alzheimer's Association, California Council

Bet Tzedek Legal Services

California Alliance for Retired Americans (CARA)

California Association of Public Authorities (CAPA)

California Church IMPACT

California Council of Churches

California Council of the Alzheimer's Association

California Council of the Blind
California Disability Community Action network (CDCAN)
California Foundation for Independent Living (CFILC)
California IHSS Consumer Alliance (CICA)
California Senior Legislature
Californians for Disability Rights, Inc. (CDR)
Communities Actively Living Independent & Free (CALIF)
Congress of California Seniors (CCS)
Dayle McIntosh Center for the Disabled
Disability Rights California (DRC)
East Bay Community Law Center
Educate.Advocate
FREED Center for Independent Living
Friends Committee on Legislation
Gray Panthers
IN SPIRIT
Independent Living Resource Center Inc.
Independent Living Services of Northern California (ILSNC)
Justice in Aging (formerly the National Senior Citizens Law Center)
Marin IHSS Public Authority
Nevada-Sierra-Plumas Public Authority
Northern California ADAPT
Older Women's League
Personal Assistance Services Council of Los Angeles
Resources for Independent Living
San Francisco IHSS Task Force

San Francisco Public Authority

SEIU Local 2015

Senior & Disability Action (SDA)

Service Employees International Union – State Council

Silicon Valley Independent Living Center (SVILC)

Southeast Asia Resource Action Center | California Office

The Arc and United Cerebral Palsy in California

The San Diego IHSS Coalition

Tri-County Independent Living Center, Inc.

UDW /AFSCME Local 3930

Westside Center For Independent Living (WCIL)

cc: Gail Gronert, Office of the Assembly Speaker
Myesha Jackson, Office of the Assembly Speaker
Chris Woods, Office of the Assembly Speaker
Nicole Vazquez, Assembly Budget Subcommittee No. 1
Cyndi Hillery, Assembly Republican Fiscal
Tyrone McGraw, Office of Assembly Member Tony Thurmond
Will Lightbourne, Department of Social Services
Robert Smith, Department of Social Services
Michael Wilkening, Health and Human Services Agency
Matt Paulin, Department of Finance
Jay Kapoor, Department of Finance
Ginni Bella Navarre, Legislative Analyst's Office
Callie Freitag, Legislative Analyst's Office

7e. DISPARITY ISSUES

College Psychology Classes Often Overlook Disabilities

by Shaun Heasley | March 2, 2016

Psychology classes at many universities pay little – if any – attention to disabilities, creating a missed opportunity to educate young people on interactions with this population, researchers say.

In an analysis of 700 classes at 98 top-ranked undergraduate psychology programs across the country, researchers found that conversations about disabilities are limited.

“About 57 million people in the U.S. have a disability, and it’s likely we will all interact with someone with a disability on a regular basis,” said Kathleen Bogart, an assistant professor of psychology at Oregon State University and an author of the study published in the journal *Teaching of Psychology*. “Yet in terms of minority groups, we teach about disability the least. We are not properly preparing students to interact with this group.”

Overall, the study found that all of the colleges in the analysis offered classes on psychiatric disabilities, but just eight had courses focusing on physical disabilities though such issues are more common. Less than 20 percent of psychology programs included opportunities to learn about physical, sensory and intellectual disabilities, the findings suggest.

Additionally, the researchers noted that courses tended to take a medical approach, focusing on diagnosis, treatment and cures rather than looking at social issues like coping, acceptance, prejudice and policy implications.

Bogart said the findings point to a need to better educate psychology faculty on disability issues and offer more resources to these teachers so that they can better incorporate such topics in their coursework.

“Ideally, disability should be infused throughout the psychology curriculum, and, in particular, it should be included in introductory, social and health psychology courses,” Bogart said. “And we should be seeing more course topics that reflect the most common types of disability.”

Big Rise in Psychiatric Hospitalizations for California's Latino Youth

By Jocelyn Wiener, California Healthline March 1, 2016

Psychiatric hospitalizations of Latino children and young adults in California are rising dramatically — at a much faster pace than among their white and black peers, according to state data.

While mental health hospitalizations of young people of all ethnicities have climbed in recent years, Latino rates stand out. Among those 21 and younger, they shot up 86 percent, to 17,813, between 2007 and 2014, according to the Office of Statewide Health Planning and Development. That's compared with a 21 percent increase among whites and 35 percent among African Americans.

No one knows for certain what's driving the trend. Policymakers and Latino community leaders offer varying and sometimes contradictory explanations. Some say the numbers reflect a lack of culturally and linguistically appropriate mental health services for Latinos and a pervasive stigma that prevents many from seeking help before a crisis hits.

“Often, they wait until they are falling apart,” said Dr. Sergio Aguilar-Gaxiola, a professor at the University of California, Davis Medical School and director of the university's Center for Reducing Health Disparities.

Others blame stress from the recent recession, family disintegration and an influx of traumatized children fleeing poverty and violence in Central America.

Still others suggest the trend might actually be positive, reflecting an increasing willingness among Latino parents to seek treatment for themselves and their children, at least when they are in crisis.

Among Latino adults, psychiatric hospitalizations rose 38 percent during the same period. Similar hospitalizations of black adults increased 21 percent, while hospitalizations of white adults remained flat.

Margarita Rocha, the executive director of the nonprofit Centro la Familia in Fresno, said mental health issues are starting to be discussed more publicly in the Latino community.

“That’s helping people to come forward,” she said.

Ken Berrick, CEO of the Seneca Family of Agencies, which serves children with emotional disturbances in a dozen counties, agreed. Because more Latinos are now getting mental health services, children are more likely to be identified as requiring hospitalization, he said.

“I know for a fact that access to service is better now,” said Berrick, whose operation has a crisis stabilization unit in Alameda County, Calif.

Kids’ psychiatric hospitalizations overall rose nearly 45 percent between 2007 and 2014, regardless of ethnicity, a pattern experts attribute to various factors including a shortage of intensive outpatient and in-home services, schools’ struggles to pay for mental health services through special education and a decline in group home placements.

“Those kids have to be treated somewhere,” said Dawan Utecht, Fresno County’s mental health director, of the move to keep kids out of group homes.

“If they don’t get those services in a community setting, they’re going to go into crisis.”

The rise among Latino youths is remarkable in part because hospitalization rates for that population historically have been relatively low.

Latino children remain much less likely to receive mental health treatment through Medi-Cal, the state and federal coverage program for poor and disabled residents. Between 2010 and 2014, less than 4 percent of Latino children received specialty mental health services through the traditional Medi-Cal program. That’s compared with 7 percent of eligible black and white children, according to state data. The numbers don’t include those enrolled in managed care.

Asian Americans and Pacific Islanders seek treatment at a rate even lower than Latinos. Although hospitalizations are also increasing rapidly among that population, the raw numbers remain relatively small.)

Leslie Preston, the behavioral health director of La Clínica de La Raza, in East Oakland, says that the shortage of bilingual, bicultural mental health workers limits Latino kids' access to preventive care, which could lead to crises later on.

"Everybody's trying to hire the Spanish-speaking clinicians," she said. "There's just not enough clinicians to meet that demand."

Access to care can be even harder for recent immigrants. Spanish-speaking children who have been referred for a special education assessment, which can help them become eligible for mental health services, sometimes wait months or years before someone tests them, she said.

"The families don't know the system," she added. "They don't know their rights."

Other clinicians point to relatively low health insurance coverage among Latinos, particularly those without legal status, and a cultural resistance to acknowledging mental illness.

Dr. Alok Banga, medical director at Sierra Vista Hospital in Sacramento, said some immigrant parents he encounters don't believe in mental illness and have not grasped the urgency of their children's depression and past suicide attempts. Many are working two or three jobs, he said. Some are undocumented immigrants afraid of coming to the hospital or having any interaction with Child Protective Services.

But the biggest problem, from his perspective, is the shortage of child psychiatrists and outpatient services to serve this population.

"The default course for treatment falls on institutions: hospitals, jails and prisons," he said.

Jeff Rackmil, director of the children's system of care in Alameda County, said sheer population growth — particularly, an increase in Latino children insured under Medi-Cal — may also be part of the explanation for the rise in hospitalizations.

Yet the state's Latino population aged 24 and under increased less than 8 percent between 2007 and 2014, which doesn't nearly explain an 86 percent increase in hospitalizations.

Some California communities are working to bring more Latino children into care and to reduce the stigma associated with mental illness.

At Life Academy of Health and Bioscience, a small, mostly Latino high school in East Oakland, students grow up amid pervasive violence and poverty. "We're just told to hold things in," said 17-year-old Hilda Chavez, a senior.

Students often don't seek help because they fear discussing mental health problems will earn them a label of "crazy," Chavez said.

Last year, the school, in conjunction with the Oakland-based La Clínica de La Raza, started a program to interest students in careers in mental health care. The program provides training in "first aid" instruction to help people in crisis, and places students in internships with mental health organizations.

Nubia Flores Miranda, 18, participated in the program last year and now is majoring in psychology at San Francisco State University. Miranda said she became interested in a career in mental health after she experienced depression and anxiety during her freshman year at Life Academy.

Seeing a school counselor "changed my life around," she said.

But she saw that her peers were wary of seeking help from counselors at the school, most of whom were white and lived in wealthier, safer neighborhoods. Once, when a classmate started acting out at school, Miranda suggested she talk to someone.

"She told me she didn't feel like she could trust the person — they wouldn't understand where she was coming from," she said.

The shortage of services is especially evident in the Central Valley, where many agricultural workers are Latino. Juan Garcia, an emeritus professor at California State University, Fresno, who founded a counseling center in the city, says the

drought and economic downturn have exacerbated depression, anxiety, substance abuse and psychotic breaks among Latinos of all ages.

“The services to this population lag decades behind where they should be,” he said.

In Fresno County, psychiatric hospitalizations of Latino youth more than tripled, to 432, between 2007 and 2014. Hospitalizations of their white and black peers about doubled.

Liliana Quintero Robles, a marriage and family therapy intern in rural Kings County, also in the state’s Central Valley, said she sees children whose mental health issues go untreated for so long that they end up cutting themselves and abusing alcohol, marijuana, crystal meth and OxyContin.

“There’s some really, really deep-rooted suffering,” she said.

Out in the unincorporated agricultural community of Five Points, about 45 minutes from Fresno, almost all of the students at Westside Elementary School are low-income Latinos. When principal Baldo Hernandez started there in 1981, he’d see maybe one child a year with a mental health issue. These days, he sees 15 to 30, he said.

He blames dry wells and barren fields, at least in part.

“I’ve had parents crying at school, begging me to find them a home, begging me to find them a job,” he said.

In some parts of the Valley and other places, the closest hospitals that accept children in psychiatric crises are hours away. Children can be stuck in emergency room hallways for days, waiting for a hospital bed.

“It makes for a very traumatized experience for both families and children,” said Shannyn McDonald, the chief of the Stanislaus County behavioral health department’s children’s system of care.

Recently, the county expanded its *promotora* program, which enlists members of the Latino community to talk to their peers about mental health.

In the small town of Oakdale, a slim, energetic 51-year-old *promotora* named Rossy Gomar spends 60 to 70 hours a week serving as cheerleader, educator and sounding board for many of the Latino women and children in the town.

“Look at my office,” she laughs. “We don’t fit.”

Gomar says many of the women she works with don’t recognize that they are depressed or abused. Children see their parents’ problems and don’t know where to turn for help.

“There are many young people who don’t have any hope,” she said.

But little by little, she has seen some good results.

One 17-year-old client is a student at Oakdale High School. The girl, whose name is being withheld to protect her privacy, said that earlier this year, problems at school and a break-up with her boyfriend had her struggling to get out of bed each morning. She began drinking, using drugs and thinking about suicide. She was scared to talk to her parents, she said, and kept everything inside.

One day, she walked into Gomar’s office and started crying.

“She told me ‘Everything is ok. We want you here,’” the girl said. “When I was talking with her, I felt so much better.”

This story was produced by [Kaiser Health News](#), an editorially independent program of the [Kaiser Family Foundation](#).

8a. DETAIL SHEETS/BILL REVIEW

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 1553, as amended, Irwin. Qualified ABLE program.

ISSUE: Should the Council support ABLE Act clean up language as requested by the State Treasurer's office?

SUMMARY: This bill would authorize the ABLE Act board to enter into a multistate contract with an account servicer in order to implement provisions and to enter into a long-term contract with an account servicer.

BACKGROUND/ISSUES/ANALYSIS: Existing federal law, the Stephen Beck, Jr., Achieving a Better Life Experience Act of 2014 (ABLE Act), encourages and assists individuals and families to save private funds for the purpose of supporting persons with disabilities to maintain their health, independence, and quality of life by excluding from gross income distributions used for qualified disability expenses by a beneficiary of a qualified ABLE program established and maintained by a state, as specified. Existing law conforms to these federal income tax law provisions relating to the ABLE Act under the Personal Income Tax Law and the Corporation Tax Law, as provided. Existing law establishes in state government the ABLE program trust for purposes of implementing the federal ABLE Act. Existing law also establishes the ABLE Act Board and authorizes the board to adopt regulations to implement the program.

DISCUSSION: The Council supported both ABLE Act bills, AB 449 (Irwin), and SB 324 (Pavley.) AB 1553 is needed to make the ABLE Act work in California.

RECOMMENDATION: Support AB 1553 (Irwin).

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 1: Individuals with developmental disabilities have the information, skills, opportunities and support to advocate for their rights and services and to achieve self-determination, independence, productivity, integration and inclusion in all facets of community life.

ATTACHMENTS: None

PREPARED: Bob Giovati

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 1821, as introduced, Maienschein. Sex offenses: disabled victims.

ISSUE: People with intellectual and developmental disabilities are sexually assaulted at a higher rate than the general population.

SUMMARY: Enhances penalties for sex crimes against people with a mental disorder/developmental or physical disability.

BACKGROUND/ISSUES/ANALYSIS: Existing law, as amended by Proposition 83, the Sexual Predator Punishment and Control Act (Jessica's Law), approved by the voters at the November 7, 2006, statewide general election, makes a defendant subject to imprisonment in the state prison for 25 years to life if convicted of certain crimes, including rape, sexual penetration, sodomy, oral copulation, continuous sexual abuse of a child, or rape, spousal rape, or sexual penetration in concert, if certain circumstances were present, including, among other things, in the commission of that offense, any person kidnapped the victim, tortured the victim, or committed the offense during the commission of a burglary, as specified.

Existing law also makes a defendant subject to imprisonment in the state prison for 15 years to life if convicted of certain crimes, including rape, sexual penetration, sodomy, oral copulation, continuous sexual abuse of a child, or rape, spousal rape, or sexual penetration in concert, if certain circumstances were present, including, among other things, in the commission of that offense any person, except as specified in the provisions above, kidnapped the victim, committed the offense during the commission of a burglary, or used a dangerous or deadly weapon in the commission of the offense. Proposition 83 provides that the Legislature may amend the provisions of the act to expand the scope of their application or increase the punishment or penalties by a statute passed by a majority vote of each house of the Legislature.

This bill would add the crimes of rape, sexual penetration, sodomy, and oral copulation, perpetrated against a person who is incapable,

because of a mental disorder or developmental or physical disability, of giving legal consent, to the above provisions, if the victim is developmentally disabled, as defined. By applying the above enhancements to these crimes, this bill would impose a state-mandated local program.

Existing law makes a defendant subject to imprisonment in the state prison for 25 years to life if convicted of certain crimes, including rape, spousal rape or sexual penetration in concert, sexual penetration, sodomy, or oral copulation if certain circumstances were present, including, among other things, in the commission of that offense, any person kidnapped the victim, committed the offense during the commission of a burglary, or used a dangerous or deadly weapon in the commission of the offense, or under other specified circumstances, and the crime was committed against a minor 14 years of age or older.

This bill would add the crimes of rape, sexual penetration, sodomy, and oral copulation, perpetrated against a person who is incapable, because of a mental disorder or developmental or physical disability, of giving legal consent, to the above provisions, if the victim is developmentally disabled, as defined. By applying the above enhancements to these crimes, this bill would impose a state-mandated local program.

Existing law requires that a person who commits certain enumerated crimes, including rape, sodomy, oral copulation, and sexual penetration, against a person who is 65 years of age or older, or against a person who is blind, deaf, developmentally disabled, a paraplegic, or a quadriplegic, or against a person who is under 14 years of age, receive a one-year sentence enhancement and requires that any person having a prior conviction for any of the enumerated offenses receive a 2-year sentence enhancement.

This bill would add to the enumerated list of crimes rape, sodomy, oral copulation, and sexual penetration, perpetrated against a person who is incapable, because of a mental disorder or developmental or physical disability, of giving legal consent. By applying the above enhancements to these crimes, this bill would impose a state-mandated local program.

DISCUSSION: See attachments.

RECOMMENDATION: None.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 4: Public Safety Outreach. The Council will maintain or develop collaborative relationships with local law enforcement agencies and others to improve the awareness and education of public safety personnel and the justice system on the unique needs of individuals with developmental disabilities.

ATTACHMENTS: Crimes Against Persons With Disabilities, The Invisible Hate Crime.

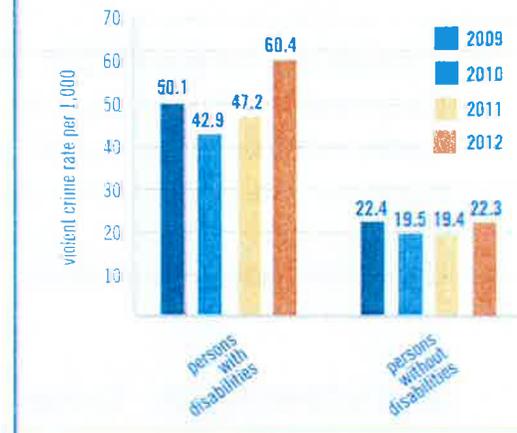
PREPARED BY: Bob Giovati

CRIMES AGAINST PERSONS WITH DISABILITIES

Persons with disabilities are victimized by crime at much higher rates than the rest of the population, and they are often targeted specifically because of their disabilities. As compared to other population groups, victims with disabilities experience higher rates of victimization by persons known to them, and they report crime less frequently, often because of the nature of their disabilities, such as cognitive or physical disabilities or mental illness. In addition to violent victimization and property offenses, crimes against persons with disabilities can also constitute a subset of hate crimes. As described more fully in the subsection devoted to hate crimes, these crimes are defined by being motivated by the offender's bias against victims of a particular group, such as those with disabilities. A majority of the information in this section relies on findings from the National Crime Victimization Survey (NCVS), which only includes those 12 and older with disabilities living among the general population in household settings. As a result, this may contribute to an underestimation of the level of violence experienced by people with disabilities as it does not take into account people living in institutions, people who are homeless or children under 12. The section concludes with several data points, compiled from a variety of other sources, about violence against children with disabilities as they are at a substantially greater risk than their non-disabled peers of being victimized.¹

- The age-adjusted violent victimization rate for persons with disabilities (60.4 violent victimizations per 1,000) was more than twice the rate among persons without disabilities (22.3 violent victimizations per 1,000) in 2012.²
- From 2009 to 2012, the age-adjusted rate of violent crime increased by 20.6 percent from 50.1 per 1,000 to 60.4 per 1,000. By comparison, the rate of violent crime against persons without disabilities decreased by 0.4 percent from 22.4 per 1,000 in 2009 to about 22.3 per 1,000 in 2012.³

VIOLENT CRIME AGAINST PERSONS WITH AND WITHOUT DISABILITIES



- In 2012, for both males and females, the age-adjusted rate of violent crime was greater for those with disabilities than the rate for those without disabilities. The rate for males with disabilities was 59.0 per 1,000, compared to 25.1 per 1,000 for males without disabilities; for females with disabilities, the rate was 61.8 per 1,000, compared to 19.5 per 1,000 for females without disabilities.⁴
- The rate of aggravated assault reported against persons with disabilities in 2009 was 6.6 per 1,000. That number increased to 10 in 2012. From 2011 to 2012, the aggravated assault rate decreased slightly from 10.5 to 10.0.⁵
- Simple assault (34.1 per 1,000 persons) was the most common form of violence utilized on persons with disabilities in 2012.⁶
- In 2012, those with cognitive disabilities had the highest unadjusted violent victimization rate (63.3 per 1,000 persons), simple assault rate (39.7 per 1,000 persons), and serious violent victimization rate (23.6 per 1,000 persons). This is also true for both male and female victims with disabilities.⁷

1 Lisa Jones et al., "Prevalence and Risk of Violence against Children with Disabilities: A Systematic Review and Meta-analysis of Observational Studies," *Lancet* 380, no. 9845 (2012): 899.

2 Erika Harrell, *Crime Against Persons with Disabilities, 2009–2012-Statistical Tables* (Washington, DC: Bureau of Justice Statistics, U.S. Department of Justice, 2014), Table 1, accessed June 6, 2014, <http://www.ojs.gov/content/pub/pdf/capd0912st.pdf>

3 Ibid., calculated from Tables 3 and 4.

4 Ibid., Table 5.

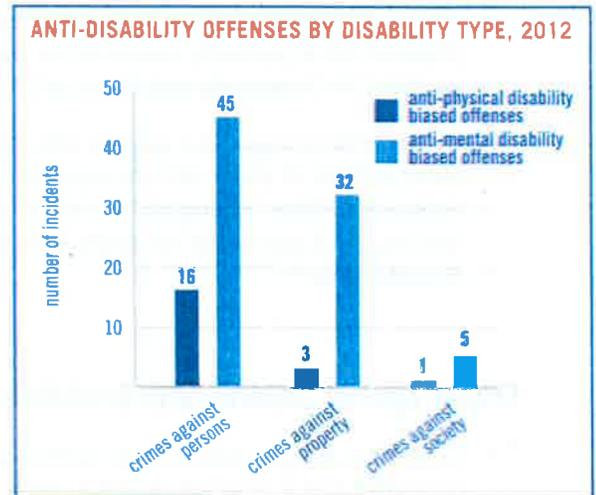
5 Harrell, *Crimes Against Persons with Disabilities, 2009–2012*, Table 3.

6 Ibid., Table 7.

7 Ibid., Tables 7, 8, and 9.

- Between 2009 and 2012, reported instances of rape/sexual assault against persons with a disability increased from 1.7 in 2009 to 3.6 in 2012.⁸
- Intimate partner violence accounted for 13 percent of violence against persons with disabilities in 2010, similar to the percentage of violence against persons without disabilities, which is 14 percent.⁹
- Offenders were strangers to the victim in 33 percent of violent victimizations against persons with disabilities in 2010, compared to 41 percent of violent victimizations against persons without disabilities.¹⁰
- Among persons with disabilities, the percentage of violence in which the victim faced an armed offender increased from 20 percent in 2008 to 30 percent in 2010.¹¹ The offender was armed with a firearm in about 14 percent of victimizations involving persons with disabilities, compared to 8 percent of victimizations against those without disabilities in 2010.¹²
- About 41 percent of the violent victimizations against persons with disabilities were reported to police in 2010, compared to about 53 percent of victimizations against persons without disabilities.¹³
- Persons with disabilities reported to the police 39 percent of robberies and 40 percent of aggravated assaults in 2010. Persons without disabilities reported much higher percentages of these crimes: 63 percent of robberies and 65 percent of aggravated assaults.¹⁴
- Crimes against disabled persons can constitute a form of hate crime. In 2007, about 19 percent of violent crime victims with a disability said they believed they had been victimized because of their disability.¹⁵

- A total of 92 anti-disability hate crimes were reported to the police in 2012. Of these, 18 were motivated by bias against persons with physical disabilities and 74 by bias against those with mental disabilities.¹⁶
- In 2012, 52.1 percent of violent crimes against people with a disability were against those with multiple disabilities, down from 56.9 percent in 2010 and up from 41.4 percent in 2009.¹⁷
- Anti-disability-biased incidents involving 102 total victims were reported to police in 2012. Of the 102 victims, 61 experienced crimes against persons, 35 experienced crimes against property, and 6 experienced a crime against society.¹⁸



- Of the 20 reported offenses against those with physical disabilities in 2012, 4 were aggravated assault, 9 simple assault, 3 intimidation, 1 larceny/theft, 1 motor vehicle theft, 1 classified as “other” crimes against property, and 1 classified as crimes against society.¹⁹

8 Ibid., Table 1.

9 Ibid.

10 Harrell, *Crimes Against Persons with Disabilities, 2008-2010*. (Washington, DC: Bureau of Justice Statistics, U.S. Department of Justice, 2011), Table 4, accessed October 6, 2014, <http://www.bjs.gov/content/pub/pdf/capd10st.pdf>.

11 Harrell, *Crimes Against Persons with Disabilities, 2008-2010*, Table 5.

12 Ibid.

13 Ibid., 5.

14 Ibid., 11.

15 Michael R. Rand and Erika Harrell, *Crimes Against People with Disabilities, 2007*. (Washington, DC: Bureau of Justice Statistics, U.S. Department of Justice, 2009), 4, accessed October 6, 2014, <http://bjs.ojp.usdoj.gov/content/pub/pdf/capd07.pdf>.

16 Federal Bureau of Investigation, *Hate Crime Statistics, 2012*. (Washington, DC: U.S. Department of Justice, 2012), Table 1, accessed June 6, 2014, http://www.fbi.gov/about-us/cjis/ucr/hate-crime/2012/tables-and-data-declarations/1tabledatadecpdf/table_1_incidents_offenses_victims_and_known_offenders_by_bias_motivation_2012.xls.

17 Harrell, *Crimes Against Persons with Disabilities, 2009-2013*, Table 6.

18 Federal Bureau of Investigation, *2012 Hate Crime Statistics*, Table 7, accessed June 6, 2014, http://www.fbi.gov/about-us/cjis/ucr/hate-crime/2012/tables-and-data-declarations/7tabledatadecpdf/table_7_victims_offense_type_by_bias_motivation_2012.xls. Crimes against society include drug-related offenses, prostitution, and animal cruelty.

19 Ibid., Table 7.

- Of the 82 offenses against those with mental disabilities, 15 were aggravated assault, 24 simple assault, 5 intimidation, 1 classified as “other” crimes against persons, 1 robbery, 3 burglary, 12 larceny/theft, 11 destruction of property/vandalism, 5 classified as “other” crimes against property, and 5 crimes against society.²⁰
- Between 2004 and 2012, victims identified disability as the perceived offender motivation in hate crimes 11 percent of the time, down from 22 percent in 2011, and the same as 2004 (11 percent).²¹
- In a national survey of over 1,300 people with disabilities and their family members in 2012, over 70 percent reported being victims of abuse. Types of abuse included verbal-emotional (87.2 percent), physical (50.6 percent), sexual (41.6 percent), neglect (37.3 percent), and financial (31.5 percent).²²
- In the same survey, 62.7 percent who reported being victims of abuse did not report the abuse to authorities. When looking at families of victims and victims, 43.3 percent of incidents were not reported to authorities.²³
- In 2012, 3.2 percent of child victims of abuse and neglect had reported a behavioral problem disability, 2.5 percent had an emotional disturbance disability, 1.1 percent reported a learning disability, 1.0 percent a visual or hearing impairment, 0.7 percent a physical disability, 0.5 percent an intellectual disability, and 4.3 percent other medical disability.²⁵
- In a review of the literature, it was estimated approximately 1 in 4 or 26.7 percent of disabled children will be a victim of violence. Of those, 20.4 percent will be victims of physical violence and 13.7 percent victims of sexual violence.²⁶
- In the same study, it was observed that children with psychological or intellectual disabilities are significantly more likely to be victims of sexual assault, compared to children with physical disabilities.²⁷
- In a study of 4,155 students in special education, children with attention deficient hyperactive disorder (ADHD) experienced the greatest risk of victimization compared to children with other disabilities. Children with emotional disturbance were the second group of disabled children most likely to experience bully victimization.²⁸ ★

Crimes Against Children with Disabilities

- In 2012, 13.3 percent of child victims of abuse or neglect had a reported disability based on data collected by the Department of Health and Human Services.²⁴

²⁰ Ibid.

²¹ Meagan Meuchel, *Hate Crime Victimization, 2004-2012—Statistical Tables*, (Washington, DC: Bureau of Justice Statistics, U.S. Department of Justice, 2014), Table 2, accessed June 8, 2014, <http://www.bjs.gov/content/pub/pdf/hcv0412st.pdf>.

²² Nora J. Baladerian, Thomas F. Colemand, and Jim Stream, *Findings from the 2012 Survey on Abuse of People with Disabilities*, (Los Angeles, CA: Spectrum Institute, Disability and Abuse Project, 2013), accessed October 6, 2014, <http://www.disabilityandabuse.org/survey/findings.pdf>.

²³ Ibid.

²⁴ *Child Maltreatment 2012*, (U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Children, Youth and Families, Children’s Bureau), Table 3–9, accessed October 6, 2014, <http://www.acf.hhs.gov/programs/cb/resource/child-maltreatment-2012>.

²⁵ Ibid., Table 3–9.

²⁶ Lisa Jones et al., “Prevalence and Risk of Violence against Children with Disabilities: A Systematic Review and Meta-analysis of Observational Studies,” *Lancet* 380, no. 9845 (2012): 899.

²⁷ Ibid.

²⁸ Jamilia J. Blake et al., “Predictors of Bully Victimization in Student with Disabilities: A Longitudinal Examination Using a National Data Set,” *Journal of Disability Policy Studies* (2014): accessed October 19, 2014, <http://dps.sagepub.com/content/early/2014/05/30/1044207314539012.abstract>.

The Invisible Hate Crime

Hate crimes against people with disabilities are widespread and often involve extraordinary levels of sadism. The first step in combating these shameful incidents is an acknowledgment that they exist.

AUTHOR:

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In February 2010, Jennifer Daugherty, a 30-year-old, mentally challenged woman from Greensburg, Pa., was brutally murdered by six people pretending to be her good friends. Holding her hostage for days, the perpetrators allegedly tortured Daugherty, shaving her head, binding her with Christmas decorations, beating her with a towel rack and vacuum cleaner, feeding her detergent, urine and various medications and then forcing her to write a suicide note, before stabbing her to death.

The sadistic attack on Daugherty was anything but unique. Still, few Americans are aware of the special vulnerability of people with emotional, intellectual and physical disabilities to extraordinary violence. Thinking of crimes inspired by hate or bias, most people conjure an image of a burning cross on the lawn of a black family, or swastikas scrawled on the walls of a synagogue. They may recall the name of James Byrd, the black American in Jasper, Texas, who was dragged for miles to his death behind a pickup truck by three white supremacists, or they might think of Matthew Shepard, the gay college student who was viciously beaten and then tied to a fence, left to die in the desert outside of Laramie, Wyo.

But the same Americans may have legal and emotional "tunnel vision," not seeing a hate crime in the brutal murder of Jennifer Daugherty, even though she was apparently singled out only because of her intellectual deficit.

Thirty-two states have hate crime statutes to protect people who have disabilities, but 18 states still do not. At the end of October 2009, President Obama signed the [Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act](#), bringing a uniform approach to the protection of hate crime victims that was not possible when matters were left to the states. The Shepard/Byrd legislation expanded federal hate crimes law to include offenses motivated by a victim's disability, gender, sexual orientation and gender identity. In addition, the new law eliminated a requirement that hate crime victims be engaged in a federally protected activity — for example, the right to live in the residence of your choice — to qualify for protection.

Still, attacks on people with disabilities are often overlooked because many people are not aware of the extreme vulnerability to maltreatment that accompanies such disorders as [cerebral palsy](#), [autism](#), [multiple sclerosis](#), learning disabilities and mental illness — even though, according to anonymous victim accounts from the [Bureau of Justice Statistics](#), the 54 million Americans with disabilities experience serious violence at a rate nearly twice that of the general population. **Their risk of being a victim of sexual assault is at least four times higher than that of people without disabilities.** In 2008 alone, Americans with disabilities were victims of about 47,000 rapes, 79,000 robberies, 114,000 aggravated assaults and 476,000 simple assaults. Adding to the trauma of victimization, people with disabilities are much less likely than able-bodied victims to seek medical treatment for their injuries, often choosing, instead, to suffer in silence.

Over the years, police departments around the country have increased their sensitivity to hate crimes based on race, religion or sexual orientation, but they still may not recognize bias against disabilities as a motivation for an assault. For the year 2009, just 97 or about 1 percent of the 7,789 hate crimes recognized by the police in FBI data reportedly targeted people with disabilities. (Of that total, 72 reports were designated as anti-mental disability crimes, and 25 were anti-physical disability crimes). This appears to represent a tremendous underestimate. When it surveyed nationally representative individuals anonymously about their experiences with crimes — even offenses not reported to the police — the Department of Justice determined that more than 11 percent of all hate crimes targeted people with disabilities. In other words, by asking victims rather than the police, the Justice Department found the number of disability attacks numbered in the thousands.

And that's not to mention another problem: Hate offenses are underreported, generally.

The FBI hate crime count is based on a voluntary reporting system that many local police jurisdictions refuse to support. In 2009, for example, only nine hate crimes were reported for the entire state of Alabama, which would reflect just one such crime per 523,190 citizens, according to Census Bureau population estimates. By contrast, other states have typically reported a much higher rate of hate crimes — for example, Massachusetts reported 322 in 2009, a rate of one for every 20,476 citizens, and New Jersey had 549 reported hate crimes, reflecting a 1-in-16,000 rate. It is hard to imagine such a huge divergence in rates arising out of anything but different reporting standards — and, perhaps, different levels of enthusiasm for reporting hate crimes at all.

Hate crimes are also underreported because motivation is a central element, and motives are often difficult to prove. The perpetrators might not have used a slur or written hate graffiti on a wall or sidewalk; they might never have confided their intent to the police or an acquaintance.

(Source: Crime Victimization Survey, U.S. Department of Justice)

In July 2006, for example, [Steven Hoskin](#), a 39-year-old man with severe learning difficulties who lived in a small English village, was violently tortured for hours in July 2006 by five people — three young adults and two teenagers — before he was forced to take dozens of painkillers and then pushed from a viaduct to his death. Pretending to be Hoskin's friends for several months before the fatal incident occurred, the five young perpetrators bullied their victim into submission on a number of occasions. The victim became convinced that he was being included as a member of a "gang" and was willing to endure pain and suffering to remain in good standing with his "good friends." The torture and murder of Steven Hoskin had no economic motive. The crime would have been impossible if Hoskin had had normal intellect. But proving that the attack was motivated by the victim's disability is not easy to do.

For many reasons, victims are themselves underreporters of hate offenses. Based on a history of animosity, black and Latino victims may see law enforcement as an "army of occupation"; immigrants may identify the police with a tyrannical regime in their home country or be concerned about being deported; gays and lesbians may perceive, rightly or not, that police officers are generally homophobic.

But violence against people with disabilities differs in important ways from other hate crimes, making attacks even less likely to be reported or acknowledged. Unlike racially and religiously motivated offenses, attacks against people with disabilities tend to be committed not by strangers but,

more often, by family members, neighbors, employees and friends who may also be caregivers.

In January 1999, eight men and women tortured a 23-year-old man with learning disabilities who worked as a cook at a fast-food restaurant in Tinton Falls, N.J. Apparently imitating the horror movie *Scream*, which they had recently viewed, the group persuaded the victim to attend a "party" and, when he arrived, tormented him for almost three hours. They stripped their victim to his underwear, slapped and kicked him and taped him to a chair that they dragged around the room. One perpetrator attempted to shave the victim's eyebrows and head with a razor; another completed the job with electric hair clippers. Members of the group then whipped him with rope knotted with a series of plastic beads, so his naked back, face and chest were covered by a network of cuts and bruises.

Cutting their victim out of the chair, they forced him to wear a bra and a woman's suit and dragged him into a van, driving him into the woods. Upon reaching a desolate area, they repeatedly punched him and slammed him to the ground. Finally, the victim was able to escape. He staggered to a nearby property, where he convinced a security guard to summon the police, who drove him to a local hospital where he was treated and released.

The victim wanted desperately to be accepted by his tormentors. Two weeks earlier, he had attended a party with the same perpetrators, who abused him and held him hostage for the evening. But he didn't file charges at the time and instead was willing to attend a second party with the same group a couple of weeks later. Even after charges of kidnapping and aggravated charges were brought against his tormentors, the victim didn't seem to appreciate the brutality of the attack, telling reporters that he "just wanted to make friends with these people."

Victims with disabilities are often extremely reluctant to report attacks out of fear that their tormentors will retaliate. They may have psychiatric or intellectual deficits that seriously interfere with their capacity to recognize false friendships or to report crime. Or they may assume a position of dependence in a relationship with caretakers who conceal their sadistic urges in the high credibility of their institutional roles. In October 2008, for example, five staff members in a Louisiana psychiatric facility were arrested for allegedly battering their patients with hand weights and inserting bleach into their open wounds. The victimized patients had complained bitterly but were perceived to be out of touch with reality and undeserving of being taken seriously.

Ignoring such hate offenses is particularly unfortunate because the level of sadism and brutality is frequently greater than in their racial and religious counterparts, and their perpetrators often engage in the sort of overkill not usually found in attacks based on other kinds of bias.

Slurs used by offenders represent the most widely employed evidence for establishing the commission of a hate attack. Racial and religious epithets are widely recognized, even by those individuals who themselves would never use them and are repulsed by those who do. The nasty labels placed on people with disabilities are just as hurtful as their racial and religious counterparts but are not recognized to the same extent. People with disabilities have been referred to as invalids (i.e., not valid persons), handicapped (capable only of begging, cap in hand) or disabled (incompetent). Other hurtful labels include crippled, deformed, feeble-minded, idiot, moron, imbecile, insane, lunatic and maniac. Often, people who wouldn't dream of using the N-word feel free to refer to an intellectually challenged individual as a "retard."

As a cultural phenomenon, racist preferences apparently find inspiration early in life, as children begin to develop the biases that they have learned

from dinner table conversations, family members, friends and television programs. In an early study by social psychologists Kenneth and Mamie Clark, preschool children were asked to choose either a black or a white doll to play with. The majority of both white and black children preferred to play with the white doll, indicating the early impact of racial subordination and segregation on the psyche of countless minority youngsters. Testimony about the Clark and Clark study was given in the landmark 1954 Supreme Court decision in *Brown v. Board of Education*, which mandated the desegregation of America's schools.

Negative perceptions of disability are also, it seems, formed very early in life. Most children aged 3 to 6 are already aware of physical disabilities and have already attributed negative characteristics to those who are not physically able-bodied. Writing in the journal *Mental Retardation*, researcher Laura Nabors notes that when able-bodied preschool children were shown pictures of persons with and without disabilities, the preschoolers showed a marked preference for able-bodied playmates and an aversion to their physically challenged counterparts. Children are more likely to learn about psychiatric and intellectual deficits later, when their cognitive abilities have developed enough to think of people who are developmentally different in unflattering terms.

Over time, what began as an aversion may easily be transformed into outright prejudice and hate. From the viewpoint of a perpetrator, the members of an out-group — defined by their physical or developmental differences — may represent a threat to his or her economic well-being, to cultural or religious values, to neighborhood composition, to educational opportunities and even to physical survival. What we might view as a hate crime is therefore often regarded by a perpetrator as *self-defense*. Hate attacks, therefore, usually occur after some precipitating event — a gay rights rally, the first Latino in a college dormitory, a developmentally

delayed student mainstreamed into a regular classroom — that is seen as calling for a "last resort" response.

As with members of racial and religious groups, individuals with disabilities have often been the victims of such "defensive" hate crimes. A couple in suburban Chicago, both of whom were dependent on wheelchairs, planned to install a ramp at the entrance of their single-family residence — until neighbors threw rocks through their windows and sent threatening letters saying, "Your kind won't last here." The couple gave up and moved away. They might have stayed in their home had they received support and encouragement from neighbors and the police; they did not.

Many hate crimes are committed by groups of young people — teenagers or young adults — who, bored and idle, are looking for a little excitement at someone else's expense. Such *thrill* hate attacks bring few practical gains to their perpetrators. Instead, they get an intangible benefit: bragging rights with friends who think that hate and violence are pretty cool. Thrill crimes are usually directed by a sadistic leader who has tremendous influence over a group of friends who may not be hate-filled but are all too eager to be accepted.

In May 2010, a 19-year-old high school student with a developmental disability was brutally attacked on a busy Boston street, in broad daylight, by a group of nine young people, ages 15 to 21. The bloodied victim, who later described himself to police as "slow and challenged," screamed and pleaded for help, then curled up on the ground, as the perpetrators repeatedly kicked, beat and choked him. The victim later told police that "the kids up the street had jumped him." He had known his assailants from the Dorchester Youth Collaborative — an agency for high-risk teenagers — and they did not like him. But the youthful perpetrators used their shared animosity as a bonding exercise. The more they shared in bashing their victim, the more cohesive their friendships became.

Some of the most dangerous hate crimes have a retaliatory motive, encouraging "tit for tat" in an exchange of violence. When the motive is retaliatory, an original attack by the members of one group is met by a retaliatory attack, often on a random basis, by the members of the victim's group. In other words, the victim becomes the villain.

On Jan. 19, 2007, John Odgren stabbed to death his 15-year-old schoolmate — a random victim — in a restroom at Lincoln-Sudbury Regional High School in Massachusetts. The 16-year-old killer had been diagnosed, early on, with major depression, Asperger's Syndrome, attention deficit hyperactivity disorder and obsessive-compulsive disorder. Because of his disabilities, Odgren had a long history of having been bullied and having sought to retaliate violently. In third grade, he threatened to shoot some girls who had harassed him. In fourth grade, he jabbed a pencil into another student's chest. He was bullied repeatedly as he bounced from school to school and finally got even with his mainstreamed peers by killing an innocent victim. For taking the life of his schoolmate, Odgren was tried, convicted of first-degree murder and sentenced to life in prison without parole eligibility.

It is important to acknowledge that some organized hate groups overtly display their hostility to disabled people in a manner that encourages nonmembers to become violent. In early November 2002, for example, the white supremacist group Stormfront allocated a section of its Web discussion forum to eugenics. Among the comments presented online was the following: "We must put into place social and economic systems that encourage the best genes to dominate in numbers as well as power."

But only a very small minority of hate crimes — perhaps 5 percent — directly involve organized hate groups. Disability hate crimes are no different in this respect.

Victims of disablist violence learn to respond in any of a number of ways to the maltreatment they are forced to endure in their day-to-day lives. In the face of widespread bias, some people with disabilities come to accept the nasty stereotypes being communicated widely about them and suffer a profound loss of self-esteem. They may see themselves as inferior, incompetent, totally disabled. Rather than regard their disability as only one of many characteristics they possess, they may instead come to define themselves totally by their most serious disadvantage and give up the struggle for self-improvement, sinking deeply into depression, drug abuse or alcoholism.

Other people with disabilities refuse to accept the nasty stereotypes that invade their lives, instead seeking to avoid the nastiest implications of their maltreatment by segregating themselves in terms of friendship, employment and dating. Rather than give up, they attempt to insulate themselves from the insulting behavior of the able-bodied.

Still others seek collectively to change the maltreatment they have suffered because of their disabilities. Since the 1970s, members of the disability rights movement have instituted boycotts, blocked traffic and engaged in a variety of protests, marches and sit-ins. Closely mirroring the civil rights and women's movements of the 1960s, organized efforts have aided in the passage of disability-rights laws and the blockage of policies that would have been hurtful to people with disabilities. In the last couple of years, hundreds of people in wheelchairs have demonstrated on the streets of Atlanta, Chicago, Washington D.C., and Nashville. In August 2008, the Special Olympics and 21 other disability groups called for a nationwide boycott of the Ben Stiller-directed film *Tropic Thunder* because of what the organizations considered a "negative portrayal" of the developmentally disabled.

Such collective efforts are important as models for what the victims of hate violence might be able to achieve in the future. For now, however, such demonstrations are typically designed to reduce employment discrimination or to discourage cuts in government budgets. The hate crime response has not yet occurred.

We don't have to change the law on hate crimes against people with disabilities — that has already happened — but we must change the thinking of ordinary people who consider only race, religion or sexual orientation as grounds for bigotry. Many people with disabilities are harmed more by the way others treat them than by their intellectual, psychiatric or physical disadvantages. This unfortunate fact has been widely ignored by otherwise decent Americans, who, when they think of hate crimes, tend to focus on people wearing sheets, armbands, steel-toe boots or Nazi tattoos. It is easy to forget that hate begins in the silence of ordinary people.

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 1824, as introduced, Chang. Guide, Signal, or Service Dogs: Injury or Death.

ISSUE: Should we provide added protections for service animals and their owners?

SUMMARY: AB 1824 will modify state law to make victims eligible for compensation through the victim's compensation fund when their guide, service or signal dog is attacked, whether or not that dog is in discharge of its duties or if the dog is in training. Additionally, this will specify that victims are eligible to receive compensation for incurred medical expenses and lost income.

BACKGROUND/ISSUES/ANALYSIS: In 2014, the legislature approved AB 2264 (Levine) which amended Penal Codes 600.2 and 600.5 relating to guide dogs. AB 2264 expanded eligibility for access to the victim's compensation fund for the owners of guide/service dogs when their dog is injured or killed.

Current law under Penal Code 600.2 states that they are eligible for reimbursement when their guide/service dog is killed or injured by another dog while Penal Code 600.5 applies to when the guide/service dog is intentionally killed or injured. Both code sections however stipulate that the guide/service dog must be in discharge of its duties for the victim to be eligible for reimbursement.

Under current law, victims are eligible for reimbursement for veterinary bills, replacement costs if the dog is disabled or killed, or other costs as deemed appropriate by the court.

Since the adoption of these regulations, members of the disabled community have developed concerns that they and their dogs may not be fully protected or properly compensated.

DISCUSSION: AB 1824 will eliminate the requirement that guide/service dogs be performing their duties when attacked in order for these laws to apply.

Throughout the day, a guide/service dog may be out in public but not performing its duties. It could even be within the boundaries of its own home when an attacking animal finds its way in. Regardless of whether or not a guide/service dog is actively performing its duties, the value and importance of the animal does not diminish. Members of the disabled community rely on these dogs to get through day to day tasks and every day without them has a major impact.

In addition to the above changes, AB 1824 will expand upon areas in which a victim may collect from the Victim's Compensation Fund. In addition to veterinary and replacement costs, AB 1824 will include medical expenses in the event that the dog owner is injured and lost income for the time they are without the services of the dog.

Finally, AB 1824 will extend these protections to include dogs that are in the process of being trained to be guide/service dogs. This will help to protect the significant investment of time and money that goes into these animals before they begin assisting the disabled. (Source: Author's fact sheet).

RECOMMENDATION: None.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 13: Generic Services: Individuals with developmental disabilities and their families have access to community based services and supports available to the general population (such as recreation, transportation, childcare, etc.) that enable them to live productive and inclusive lives.

ATTACHMENTS: None.

PREPARED: Bob Giovati.

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 2231, as introduced, Calderon. Care facilities: civil penalties.

ISSUE: Existing law establishes the State Department of Social Services and sets forth its powers and duties, including, but not limited to, the licensure and regulation of community care facilities, residential care facilities for persons with chronic life-threatening illnesses, residential care facilities for the elderly, day care centers, and family day care homes. Existing law authorizes the department to impose various civil penalties for a licensing violation under those provisions, as specified, and requires moneys collected from the imposition of those penalties to be expended for certain purposes. Existing law establishes a process for the appeal of a citation under these provisions.

SUMMARY: In 1985 the California Residential Care Facilities for the Elderly Act established a civil penalty structure for violations in facilities; the Act set the minimum civil penalty at \$25 and the maximum penalty at \$150 per day per violation. It also permitted additional civil penalties be issued for repeat violations within a 12-month period. In 2014, Governor Brown signed into law AB 2236 (Maienschein), which, among other things, increased civil penalties for RCFEs to \$15,000 for incidents that were determined to have resulted in death, and up to \$10,000 for incidents that were determined to have resulted in serious bodily injury, or constituted physical abuse. However, the increased civil penalties provided for in AB 2236 did not extend to less serious violations.

BACKGROUND/ISSUES/ANALYSIS: Current law allows for the California Department of Social Services to levy civil penalties ranging from \$1,000-\$15,000 depending on facility type, against facilities where violations are determined to have resulted in death or serious bodily injury or to have constituted physical abuse. Current law also provides for an appeals process for licensees to request a review of cited violations.

AB 2231 does the following: Increases penalties for “less serious” violations in care facilities in line with reforms in recent years, and adopts a penalty structure for repeat violations in care facilities. This bill will maintain the civil penalties provided for in AB 2236 to ensure that the severity of a crime is met with appropriate penalties, and will ensure that the concerns of small facilities are addressed in order to preserve availability for those in need of care. California Department of Social Services in the sponsor.

RECOMMENDATION: None.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 4: Public Safety Outreach. The Council will maintain or develop collaborative relationships with local law enforcement agencies and others to improve the awareness and education of public safety personnel and the justice system on the unique needs of individuals with developmental disabilities.

ATTACHMENTS:

PREPARED: Bob Giovati

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 2383, as introduced, Medina. Autism Employment and Education Act.

ISSUE: Should the legislature address the low employment and education rates of people impacted by Autism Spectrum Disorder (ASD), and is this bill the proper one by which to do so?

SUMMARY: This bill would establish the Autism Employment and Education Program, which would establish a residential, occupational, and living skills program at each participating community college and California State University campus to help students with mental disabilities, including autism, live independently, obtain employment, and become otherwise self-sufficient after they graduate or withdraw from the college or university.

The bill would establish the Autism Employment and Education Fund in the State Treasury and allocate moneys in the fund, upon appropriation by the Legislature, to the board of governors and the trustees for the development, implementation, and administration of the program. The bill would only become operative upon appropriation by the Legislature for the implementation and administration of the program

BACKGROUND/ISSUES/ANALYSIS: It is the intent of the Legislature that implementing a residential, occupational, and living skills program for students with mental disabilities, including autism, will accomplish all of the following objectives:

(A) The program will increase the rate of employment of students with mental disabilities from its current level of around 25 percent to 85 percent.

(B) The program will be a more affordable alternative for families than adult day treatment programs, which may cost nearly twice as much.

(C) The program will enable participating students to live independently, to learn the life skills necessary to become lifelong productive members of their local communities in California, and to not need to relocate out of state in order to receive affordable services.

(D) The program will provide students with mental disabilities a more coordinated continuity of care by incorporating all of their living skills, occupational, social, and recreational development needs into one program.

DISCUSSION: According to a report published in April 2012 by the Autism Society of California, "The majority of transition aged families (98 percent) believed that current adult programs are not going to meet their loved-one's needs." Additional findings from this report indicated that only 5 percent of people with ASD graduated from college with a bachelor's degree and only 3 percent graduated with a master's or an associate degree.

About 12 percent of students with ASD go to college and do not succeed; this is lower than the national average of 14 percent. The number of people with ASD in California remaining at home and not participating in any type of postsecondary educational program is on the rise, going from 13 percent in 2009 to 18 percent in 2012.

According to the Department of Labor Statistics, the unemployment rate for individuals with disabilities is 78.5 percent.

RECOMMENDATION: None.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 8: Employment First: The State of California will adopt an Employment First policy which reflects inclusive and gainful employment as the preferred outcome for working age individuals with developmental disabilities.

ATTACHMENTS: None.

PREPARED: Bob Giovati

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: SB 982, as introduced, McGuire. Developmentally Disabled Persons: Conservatorships and Guardianships.

ISSUE: Conservatorships and Guardianships.

SUMMARY: Gives added time to file an affidavit or certificate regarding guardianships and conservatorships.

BACKGROUND/ISSUES/ANALYSIS: Existing law authorizes the Director of Developmental Services, upon nomination and acceptance, to be appointed as either guardian or conservator of the person or estate, or both, of a developmentally disabled person.

Existing law provides that the director may petition for his appointment to act as conservator or guardian in the superior court of the county where the main administrative office of the regional center serving the developmentally disabled person is located.

Existing law requires the alleged developmentally disabled person to be present at the hearing if he or she is within the state and is able to attend. Existing law provides that if he or she is unable to attend the hearing by reason of physical or other inability, that inability shall be evidenced by the affidavit or certificate of a duly licensed medical practitioner, as specified. Existing law requires that the affidavit or certificate be filed no later than 10 days prior to the time of the hearing.

This bill would instead require the affidavit or certificate described above to be filed no later than 5 days prior to the time of the hearing. The bill would also make technical, nonsubstantive changes to these provisions.

DISCUSSION: If the alleged developmentally disabled person is within the state and is able to attend, he or she shall be present at the hearing. If he or she is unable to attend by reason of physical or other inability, such that inability shall be evidenced by the affidavit or certificate of a duly licensed medical practitioner as provided in Section 1825 of the Probate Code. The affidavit or certificate shall be filed no later than five business days prior to the time of the hearing.

RECOMMENDATION: Support SB 982 (McGuire).

COUNCIL STRATEGIC PLAN OBJECTIVE : Goal 2: Rights training and advocacy. Individuals with developmental disabilities and their families become aware of their rights and receive the supports and services they are entitled to by law across the lifespan, including early intervention, transition into school, education, transition to adult life, adult services and supports, and senior services and supports.

ATTACHMENTS: None.

PREPARED: Bob Giovati

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: SB 1034, as introduced, Mitchell. Health care coverage: autism.

ISSUE: Health and Safety Code Section 1374.73 and Insurance Code Section 10144.51 require coverage for behavioral health treatment for children with autism. In addition, these sections outline the how the coverage will be applied and who may provide treatment. Both sections sunset in 2017. Legislation is necessary to ensure continued coverage

SUMMARY: SB 1034 will ensure that children diagnosed with autism have access to medically necessary treatments to increase their quality of life and functional independence by removing the (2017) sunset on the requirement for health plans and insurers to provide behavioral health treatments to children with autism.

In addition, this bill makes the following changes to the existing autism insurance mandate:

- Updates the definition of behavioral health treatment to ensure coverage for interventions designed to maintain functioning, which is critical to children with autism.
- Clarifies the roles of a qualified autism service professional and qualified autism service paraprofessional.
- Limits unnecessary treatment plan reviews and clarifies that medically necessary services cannot be denied based on time and location of delivery.
- Removes the requirement for providers to be approved as a vendor by a California Regional Center, but retains the same qualifications.

BACKGROUND/ISSUES/ANALYSIS: In 2011, landmark legislation was signed into law, SB 946 (Chapter 650), to require all health insurance plans to provide coverage for behavior health treatment for pervasive developmental disorder or autism. At the time SB 946 was signed there were a number of outstanding questions with regards to mandated benefits, the Affordable Care Act (ACA), and the State's fiscal responsibility. Because of this, SB 946 included a sunset in 2014 to provide an opportunity for the legislature to revisit the issue after receiving guidance from the federal government on the implementation of the essential health benefits (EHB) under the ACA. That sunset was later extended in 2013 to 2017 (SB 126) and passed with bipartisan support.

The federal government has since provided guidance on selection and implementation of the EHBs. In addition, the Department of Managed Health Care has determined that behavioral health treatments for autism are covered under California and Federal

Mental Health Parity which extended coverage to the Healthy Families Program and CalPERS plans that had been exempt for fiscal reasons.

Finally, SB 946 did not provide coverage for Medi-Cal recipients. However, earlier this year the Department of Health Care Services received federal approval to provide behavioral health services to children with autism under the age of 21.

DISCUSSION: Since the passage of SB 946, countless children have received treatment through their health plans. Prior to the passage of SB 946, families (with health insurance) often paid upwards of \$50,000 per year. In the process, many risked their homes and the educations of their unaffected children – essentially mortgaging their entire futures. Alternately, services were provided by regional and developmental centers at a high cost to the state. Removing the sunset of the California autism insurance mandate will allow children with autism to continue to receive medically necessary behavioral health treatment from qualified autism service providers. (Source: Author's fact sheet).

RECOMMENDATION: Support SB 1034 (Mitchell).

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 10: Health: Individuals with developmental disabilities understand their options regarding health services and have access to a full range of coordinated health, dental and mental health services in their community.

ATTACHMENTS: None.

PREPARED: Bob Giovati.

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: SB 1221, as introduced, Hertzberg. Firefighters: Interaction with Mentally Disabled Persons.

ISSUE: Should a training course relating to law enforcement interaction with people with I/DD be offered to firefighters as well?

SUMMARY: Existing law requires the Commission on Peace Officer Standards and Training to establish a continuing education classroom training course related to law enforcement interaction with mentally disabled persons and to make the course available to law enforcement agencies in California. This bill would authorize the commission to make the course available to firefighters and fire departments in California. The bill would delete an obsolete reporting requirement and make a conforming change.

BACKGROUND/ISSUES/ANALYSIS: The Commission on Peace Officer Standards and Training shall establish and keep updated a continuing education classroom training course relating to law enforcement interaction with mentally disabled persons. The training course shall be developed by the commission in consultation with appropriate community, local, and state of California, and may make the course *available* to firefighters and fire departments in California. The course described in subdivision shall consist of classroom instruction and shall utilize interactive training methods o ensure that the training is as realistic as possible.

DISCUSSION: Generally speaking, the more training first responders can get regarding this topic, the better.

RECOMMENDATION: None.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 4: Public safety outreach. Public safety agencies, other first responders and the justice system get information and assistance to be knowledgeable and aware of the needs of individuals with developmental disabilities so they can respond appropriately when individuals with developmental disabilities may have experienced abuse, neglect, sexual or financial exploitation or violation of legal or human rights.

ATTACHMENTS: None.

PREPARED BY: Bob Giovati.

LPPC AGENDA ITEM DETAIL SHEET

BILL: SB 1252, as introduced, Stone. Health Care Costs: Patient Notification.

ISSUE: As a result of a lack of clarity regarding health plan provisions, some people are being confronted with medical bills they were not anticipating. This can be particularly problematic for people with cognitive deficits, or living on fixed incomes.

SUMMARY: SB 1252 provides patients with more accurate information regarding out of pocket medical costs.

BACKGROUND/ISSUES/ANALYSIS: Existing law provides for the licensure and regulation by the State Department of Public Health of health facilities, including general acute care hospitals and surgical clinics. The Medical Board of California licenses and regulates physicians and surgeons, and the Osteopathic Medical Board of California licenses and regulates osteopathic physicians and surgeons.

This bill would require, when a medical procedure is scheduled to be performed on a patient, the general acute care hospital, surgical clinic, and the attending physician, as applicable, to notify the patient, in writing, of the net costs to the patient for the medical procedure being done, as provided.

For complex medical procedures or screenings involving multiple physicians, the general acute care hospital, surgical clinic, and attending physician, as applicable, would be required to disclose, in writing, if any of the physicians providing medical services to the patient are not contracted with the patient's health care service plan or health insurer and the costs for which the patient would be responsible as a result. The bill would provide that a violation of these provisions by a physician and surgeon or osteopathic physician and surgeon would constitute unprofessional conduct, as provided.

DISCUSSION: Unanticipated medical costs can be financially devastating, particularly for people on fixed incomes. Convoluting provider networks and confusing health plan language can be difficult to understand. A particular procedure may be rendered by a number of different medical professionals and facilities, some in-network, some not.

In an effort to address this issue, SB 1252 does the following:

When a medical procedure is scheduled to be performed on a patient, the general acute care hospital, surgical clinic, and the attending physician, as applicable, shall notify the patient, in writing, of all of the following: The net costs to the patient for the medical procedure being done, including, but not limited to, all of the following: Applicable copayment, coinsurance, or deductible. The full cost of the medical procedure. The range of costs for a stay in a general acute care hospital or surgical clinic. A complete and precise breakdown of the costs the patient's health care service plan or health insurer will pay and the costs for which the patient will be responsible.

For complex medical procedures or screenings involving multiple physicians, the general acute care hospital, surgical clinic, and attending physician, as applicable, shall disclose, in writing, if any of the physicians providing medical services to the patient are not contracted with the patient's health care service plan or health insurer and the costs for which the patient will be responsible as a result.

RECOMMENDATION: None.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 1: Self Advocacy: Individuals with developmental disabilities have the information, skills, opportunities and support to advocate for their rights and services and to achieve self-determination, independence, productivity, integration and inclusion in all facets of community life.

ATTACHMENTS: None.

PREPARED: Bob Giovati

COUNCIL AGENDA ITEM DETAIL SHEET

ISSUE: Should the Council support driverless cars as a way to enable increased mobility for people with intellectual and developmental disabilities (I/DD)?

SUMMARY: Driverless cars could potentially open up entirely new horizons for individuals who are not themselves able to drive.

BACKGROUND/ISSUES/ANALYSIS: Driverless cars are the wave of the future. Because the concept is so new, the state is trying to determine how these vehicles will be regulated.

Current proposals suggest that an able-bodied individual/operator would have to be in the car in order to take control in the event of a malfunction. However, if this becomes the law, it will severely limit the ability of people with I/DD to utilize self-driving vehicles.

DISCUSSION: Driverless cars should not become simply another expensive technological novelty item. There is real potential here to drastically improve the lives of individuals with mobility issues. The Council should make every effort to see that laws regulating self-driving vehicles are written to maximize benefits for people with I/DD.

RECOMMENDATION: Support driverless car regulations that are the most inclusive of people with I/DD.

COUNCIL STRATEGIC PLAN OBJECTIVE: Support all 15 State Plan goals.

ATTACHMENTS: Article, "Will Driverless Car Regulations Leave People with Disabilities Behind?"

PREPARED: Bob Giovati

Will Driverless Car Regulations Leave People with Disabilities Behind?

Date: February 24, 2016

Author(s): [John E. Brown](#), [Thomas Rice](#) and [Marc Tran](#)

Topics: [General Public Law](#), [Public Safety](#)

Earlier this month, the California Department of Motor Vehicles [hosted public workshops to discuss its proposed regulations for the deployment of autonomous vehicles](#). Many advocates for people with disabilities voiced their concern that the regulations in their current form could preclude use of autonomous vehicles by people who have the most difficulty getting around.

In its current form, the DMV's proposed regulations would require an able-bodied operator to assume operation of the vehicle in case of a technology failure. This would exclude use by people with disabilities who are not able to operate a traditional vehicle. Advocates have argued this does not have to be the case because regulatory and technological remedies are readily available.

As to regulatory solutions that might address these concerns, the National Highway Traffic Safety Administration recently expressed willingness to consider an autonomous vehicle's operating system as a driver. This expansive definition of what constitutes a driver could provide increased accessibility for people with disabilities. If the definition of a "person" can be expanded to include business entities such as corporations, for example, then the definition of a "driver" could be expanded to include an autonomous vehicle's operating system. Many argue the DMV's regulations are not forward-thinking enough because they require traditional operating mechanisms (e.g., steering wheels and brake pedals) and, as a consequence, require able-bodied operators that can make use of those mechanisms.

As to a technological solution, the technology required to put people with disabilities behind the wheel already exists. In 2011, [Dr. Dennis Hong and his team of roboticists built a vehicle equipped with non-visual interfaces that allowed people with visual impairments to make active decisions and safely operate a vehicle](#). The vehicle was equipped with technology that obtained information from its environment and relayed it in a non-visual manner through the use of vibrations (transmitted through gloves and the driver's seat) and compressed air (capable of changes in frequency and temperature to convey a change in environment).

The operating systems in autonomous vehicles currently being tested already collect information from their environments and translate it into data that can be processed by the vehicle itself (e.g., lane width, distance to objects, etc.). Disability rights advocates are asking that an additional translation be added that can be interpreted by people with visual impairments to greatly expand access to this valuable technology.

Autonomous vehicles offer the promise of greater independence and mobility for people with disabilities. At present, the DMV has proposed regulations that need to recognize these potential advances. From the standpoint of people with disabilities, such regulations should not simply preserve the status quo; they should recognize that people with disabilities cannot operate traditional vehicles and cannot use autonomous vehicles. By reserving use of autonomous vehicle technology to drivers that could operate a traditional vehicle, regulators appear to be missing an opportunity to allow new technologies to greatly expand access to autonomous vehicles. In the same way that the DMV regulations have been modified over the decades to permit greater access to conventional automobiles, with approved technological modifications, we should consider doing the same thing from the inception with driverless technologies.

- See more at: <http://www.bbknowledge.com/public-safety/will-driverless-car-regulations-leave-people-with-disabilities-behind/#sthash.CbnEj9y0.dpuf>

