



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

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PARTICIPANT CODE:**

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

DATE: February 8, 2016

TIME: 10:00 a.m. to 3:00 p.m.

LOCATION: State Council on Developmental Disabilities
1507 21st Street, Suite 210
Sacramento, CA 95811
(916) 322-8481

TELECONFERENCE SITE(S):

Central Coast Office
200 E. Santa Clara, Suite 210
Ventura, CA 93001
(805) 648-0220

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 February 2, 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 NOVEMBER 10, 2015 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/
Other Organizations | B. Giovati | 15 |
| b. IHSS/CMS Updates/Overtime Discussion | C. Lapin/All | |
| c. Federal & State Legislation Updates/Council
Update on LPPC Bill Package & Other Bills | B. Giovati/
N. Nieblas | 25 |
| d. Self-Determination | C. Lapin/All | |
| i) Update on Person Centered Planning | | |
| ii) Statewide SDP Committee | | |
| e. Disparity Issues | All | 73 |

8. NEW BUSINESS

- a. Bagley-Keene Questions N. Bocanegra/
All
- b. State Plan Goals/Legislative Priorities 2016 J. Lewis/All
- c. Council Strategy at Capitol All
- d. 2016 LPPC Meetings/SCDD Structural Deficit All
- e. Press Outreach N. Nieblas

9. ADJOURN

J. Lewis



DRAFT

LPPC Committee Meeting Minutes
DATE: November 10, 2015

Attending Members

David Forderer (SA)
Sandra Aldana (SA)
Jennifer Allen (SA)
Lisa Davidson (FA)
Connie Lapin (FA)
Tho Vinh Banh

Members Absent

Janelle Lewis (FA)
April Lopez (FA)

Others Attending

Nelly Nieblas
Bob Giovati
Michel Brett
Wayne Glusker

1. CALL TO ORDER

Chairperson Janelle Lewis (SA) was not present for this meeting. Therefore, Lisa Davidson (FA) is the acting chair and called the meeting to order at 10:25 a.m.

2. ESTABLISH QUORUM

A quorum was established.

3. WELCOME/INTRODUCTIONS

Members and others introduced themselves as indicated.

4. MEMBER REPORTS

Jennifer Allen (SA): No report given.

Lisa Davidson (FA):

- Stated that the Los Angeles Regional Office held their last RAC meeting in October 2015. This meeting consisted of brainstorming on legislation/ideas. During this meeting, the committee met the new Los Angeles Regional Manager, Cindy Chiu.
- Accolades were given to Vicki Smith as the interim Regional Manager for the LA Office.

Legend:
SA = Self-Advocate
FA = Family Advocate

Connie Lapin (FA): Gave the following reports:

- The Autism Society of Los Angeles will be holding a conference called It's a New Day. This conference is on the Self Determination Program and the new Federal Mandates on Inclusion. The conference takes place at the Double Tree Hilton in Los Angeles on February 18-19, 2016. Scholarships will be offered for individuals that cannot afford to attend.
- Discussed that a new story book on autism, *In a Different Key*, is coming out January 2016. Mr. and Mrs. Lapin are mentioned in the book.
- Discussed a state auditors' report on regional centers to see if these centers are using least cost providers.
- Mentioned that during July – September 2015, 515 hearings were filed by I/DD individuals and only 7 of these hearings were heard with only 1 being granted.

Tho Vinh Banh: Gave the following reports:

- Discussed that IHHS updates/related changes are on the DRC Website.
- Mrs. Banh shared that she conducted a training session to a Spanish speaking group on Self/Determination/other issues. It was determined that these training materials should also be translated into other languages like Chinese, Vietnamese, Korean, etc.
- Mentioned that HR 2646, a federal bill similar to HR 3717, could prevent Protection and Advocacy organizations like DRC from lobbying and advocating for individuals with psychiatric disabilities. As a result of this, the State Council has placed an opposition on this bill.
- Discussed issues on hiring/elections of the new Executive Director for Westside Regional Center.
- Mentioned there has been a change on the trailer bill for Disparity Issues.
- Discussed problems with translations on IPPs in the Regional Center system.
- Suggested a change to the law:

- Pair-up with **Medical** standards on language translation thresholds per county.
- Discussed educating people on getting their IPPs done in 45 days.
- Discussed that publications need to be created for threshold languages that do not fit.
- Discussed publications translated into different languages explaining these rights.

Mrs. Banh feels that the State Council can play a role with these issues on getting information out to the communities in different threshold languages. Bob Giovati, Deputy Director of Policy and Planning, suggested this topic would be good for the State Plan Committee (SPC) to examine, as the SPC is getting information/documentation translated into the threshold languages.

Aaron Carruthers, Executive Director, and staff discussed opportunities regarding threshold language translations.

Committee and staff further discussed the subject of disparities.

Chairperson Davidson (FA) gave a suggestion that SCDD staff and Mrs. Banh will work together on these concerns. Also, it was agreed to ask Janelle Lewis (FA), committee chair to have disparity issues as an item on future agendas.

David Forderer (SA): Discussed how law enforcement does not know how to interact with I/DD individuals. This is a big concern state wide. Committee agreed this issue should be further discussed.

5. APPROVAL OF THE SEPTEMBER 21, 2015 MEETING MINUTES

It was moved/seconded (Lapin)(FA), (Allen)(SA) and carried to approve the September 21, 2015 meeting minutes with corrections. There were no abstentions. (All in favor. See attendance list for voting members)

Corrections:

Page 5: Remove the last two sentences from Ms. Davidson's Member Report.

Pages 6 and 7: Correct the spelling from Bahn to Banh.

6. PUBLIC COMMENTS

Legend:
SA = Self-Advocate
FA = Family Advocate

Page 3

A written public comment was presented to the committee from Safika Erselcuk, who is a parent from Los Angeles. Her letter is concerning SB-277 – Public Health – Vaccinations Implementation. This letter was read to the committee by Chairperson Davidson (FA). The committee recommended adding this issue to future agendas.

To view this letter, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%206.pdf>

There were also two other public comments that were presented to the committee by teleconference:

Gabriela Ahlhim from Corona Unified School District:

- Is a parent with two children that are on IEPs with one child she says is vaccine injured. Ms. Ahlhim has concerns with SB 277 and its implementation. With the implementation of the law, parents in her school district/others will start be reported to the truancy department if their children are not vaccinated. As a result, parents will have to go to truancy court.
- She would like this committee/DRC to get involved regarding how each school district will handle the implementation process.
- Another concern is that health professionals can administer vaccines on campus, which could affect the wellbeing of an I/DD child.
- The committee held a discussion concerning this matter, and agreed to follow-up on it in the future.

Kristie Burchit, parent and the Executive Director of Educate Advocate:

- Expressed concerns regarding IHSS overtime implementation, and that a fix is needed on the caps that affect families.
- Mentioned Social Security Day of Action started today, November 10, 2015.
- Stated that service providers need increases.
- Voiced the following concerns with SB 277:
 - This bill is still unclear for students that are on IEPs.
 - Dealing with truancy courts.
 - CDPH and CDE will determine the interpretation of SB 277.

Legend:
SA = Self-Advocate
FA = Family Advocate

Chairperson Davidson (FA) then thanked the above public presenters.

7. OLD BUSINESS (Standing Items)

a. Budget Update/Special Session

Deputy Director Giovati commented that not much has changed legislatively since the last LPPC meeting which took place September 21, 2015.

The committee then held a general discussion concerning the upcoming state budget.

b. IHSS and CMS Updates

Discussed the DS Taskforce regarding IHSS/Overtime and the Managed Care Organization Tax. Mrs. Lapin (FA) mentioned uncertainty regarding when overtime/implementation retroactive payment is going to take place.

Mrs. Lapin (FA) continued to brief the committee on the following:

- Overtime funding/no retroactive payment.
- Overtime rate adjustment of 5.82 percent.
- DS Taskforce recommends that the rate adjustment takes effect immediately.
- CMS rules with supported living.
- What are the exemptions?
- Supported Living Agencies taking care of I/DD individuals.

Deputy Director Giovati offered input on these topics.

Executive Director Carruthers mentioned he attended a meeting of the Secretary of the State Taskforce which he is a member of. He made the following points to the committee:

- Our field may not see new funding. Proposed new state budget to be announced in January 2016.
- We will have to see how the governor will bridge the 1.1 billion dollar hole that will be left regarding MCO tax and legislature.

- May even see reductions.

Mrs. Lapin (FA) presented a health network alert on Justice in Aging titled: *Action Steps to Prevent Service Cuts and Protect Consumer-Directed Programs as New Home Care Rules Takes Effect.*

To view this health network alert, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%207b1.pdf>

Additional information presented by Mrs. Lapin (FA) on overtime and related changes can also be viewed on the SCDD Website. Please go to the link below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%207b2.pdf>

Staff and committee continued to discuss this agenda item. Executive Director Carruthers discussed the following in regard to Self-Determination:

- State submission of the Self-Determination waiver regarding CMS.
- Self-Determination waiver may not be approved until the final rule waiver is approved.
- Discussed manage care.

The committee engaged in further discussion on these topics.

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

Deputy Director Giovati briefed the committee on this agenda item in regards to SCDD supported legislation. A handout was given to the committee on the bills. Emphasis was placed on the following SCDD supported bills: AB 74, AB 918, AB 1261, and SB 324.

To see the above handout in its entirety, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%207c.pdf>

In regard to the two ABLE Act Bills, the State Council will be involved with the Treasurer's office on the rollout of these bills. Deputy Director Giovati and State Council Chair, Dr. April Lopez (FA), will be attending an initial meeting with the Treasury office, November 20, 2015.

Chairperson Davidson (FA) gave accolades for the staff work/future involvement with these bills.

Committee then held a discussion over this agenda item.

d. Self-Determination

Mrs. Lapin (FA) briefed the committee on Self-Determination:

- Held a Self-Determination Workgroup meeting with a lot of public participation/information.
- Discussed feedback from Regional Centers.
- Discussed Self-Determination Waiver went out and was submitted on September 29, 2015.
 - Future information to follow.
- Talked about new FAQs on the DDS Website.
- Offered a Training Subgroup Update.
- Mentioned that training modules will be in place December 2015.

i. Self-Determination

Committee agreed to table until the next meeting.

ii. Statewide Self Determination Program

- Dr. Lopez (FA), Council Chair and committee member, read the letter that the State Council is going to convene the Chairs of the Local Advisory Committees.
- Executive Director Carruthers and Chairperson Davidson (FA) discussed a possible February 2016 Statewide meeting date for the Local Advisory Committee chairs.

8. NEW BUSINESS

a. State Plan Goals/Legislative Priorities 2016

Committee heard that staff has been working with the different Regional Advisory Committees (RAC), throughout the State Council, to

come up with Legislative ideas for 2016. It was then turned over to Deputy Director Giovati.

Deputy Director Giovati then went on to explain that he has been working with Mrs. Lewis (FA), receiving input from various staff/Regional Managers, and RACs on these legislative ideas.

A handout was then given to the committee titled, *Potential Legislative Ideas for 2016*. Staff then explained how the handout was worked out and coordinated with the Chair, Mrs. Lewis (FA). To view this handout, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%208a1.pdf>

Staff requested the committee go over the list of ideas from this handout and determine which ones they would like to pursue. Once the committee determined what ideas they would like to do further work on, staff would work up a detail sheet and present it to the full Council for determination.

The committee/staff then held a brainstorming session on the *Potential Legislative Ideas for 2016* and came up with the following interest items:

1(DRC co-sponsor), **12**, **14**(DRC possible co-sponsor), **17**, **19**(CECY/EFC: Three ideas for proposed bill introduction from the EFC), **22**, **25**, **27**, **30**, and **31**(The last four ideas are interests from the Los Angeles Regional Office/DRC co-sponsor for item **31**).

It was also determined to come back to other interest items:

5(DRC co-sponsor), **7**, **15**, **24**, **28**, and **33**(The last three ideas are interests from the Los Angeles Regional Office).

Executive Director Carruthers mentioned he has been in talks with Catherine Blakemore regarding SCDD and DRC possibly co-sponsoring legislation together. The committee approved of this idea.

The committee suggested the State Council co-sponsor with the DRC in the following issue areas:

Items **2**, **3**, and **5**. Other interest areas: Levels for sexual assaults (*page 7, Proposal) and protection housing, under FEHA, for individuals that are in Sheltered Workshops (*page 10, Proposal).

It was recommended by committee/council member, Dr. Sandra Aldana (SA) to have staff cross reference and mark these agreed/other interests with the federal areas of interest. Staff will present this to the committee during the next LPPC meeting.

***NOTE:** A handout from DRC was then passed out to the committee explaining their legislative priorities. To view this handout, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%208a2.pdf>

Executive Director Carruthers went over next steps to present these ideas to the full Council with a detail sheet:

- Presenting these concepts.
- DRC co-sponsoring.

Committee and staff agreed on the above procedure.

b. Press Outreach

Committee agreed to table to next meeting.

c. Civic Activities

Mrs. Banh gave/went over a handout from the DRC on the SB 35, National Voter Registration Act of 1993. She then gave/went over another handout on the same issue from DDS which was given to all the Executive Directors from the Regional Centers. To view these handouts, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%208c1.pdf>

Natalie Bocanegra, staff Council, was asked by the committee to answer any questions regarding involvement in political activities regarding the 2016 Presidential elections. Ms. Bocanegra responded with the following answers:

- The State Council will not and cannot engage with political activities.
- Under the DD Act, the State Council has a mandate to advocate.

- Our funding source, AIDD, has issued guidance with regards to the types of activities to the grantees (State Council). Needs to be presented in an objective/informational way.
- Discussed a document from AIDD on lobbying instructions.

Ms. Bocanegra then gave a summary to the committee. To view this summary, please go to the SCDD Website. The link is located below:

<http://www.scdd.ca.gov/res/docs/pdf/LPPC/2015/LPPC-%20Handout%20Item%208c2.pdf>

- With regards to policy makers, communication needs to inform and educate. Needs to be very informative.
- With regards to candidates, it depends on the purpose of the communication.
- Discussed ballot measure activities.
- Use of public funds.
- Not getting involved with the political aspect/influencing voters for or against a ballot measures, etc. Communications need to be very informational.

Committee stated they are interested in individuals with disabilities being registered to vote. The committee would like individuals with disabilities to have a voice. Ms. Bocanegra responded by saying yes there are certain objectives to follow under the DD Act with voter registration issues. The following recommendations were given:

- Training.
- Conducting studies/gathering information for reports.
- Registering people themselves may not be appropriate.

Mrs. Banh then gave a briefing on existing law for voting. This law is to ensure the Regional Centers know what the requirements are. She explained that the Regional Centers need to be held legally accountable.

SB 35 requires reporting on a database. This is used to show numbers from the different Regional Centers and Voter Registration Agencies.

d. Discussion Items on IDD and Law Enforcement

No discussion took place.

9. ADJOURN

Meeting adjourned at 3:05 p.m.

Governor's Budget Highlights



**Edmund G. Brown Jr.
Governor
State of California**

**Diana S. Dooley
Secretary
California Health and Human Services Agency**

**Michael Wilkening
Acting Director
Department of Developmental Services**

January 2016

DEPARTMENT OF DEVELOPMENTAL SERVICES GOVERNOR'S BUDGET HIGHLIGHTS

PROGRAM HIGHLIGHTS

The Department of Developmental Services (Department or DDS) is responsible under the Lanterman Developmental Disabilities Services Act (Lanterman Act) for ensuring that approximately 290,000 persons with developmental disabilities receive the services and support they require to lead more independent and productive lives and to make choices and decisions about their lives.

California provides services and supports to individuals with developmental disabilities two ways: the vast majority of people live in their families' homes or other community settings and receive state-funded services that are coordinated by one of 21 non-profit corporations known as regional centers. A small number of individuals live in three state-operated developmental centers and one state-operated community facility. The number of consumers with developmental disabilities in the community served by regional centers is expected to increase from 290,496 in the current year to 302,419 in Fiscal Year (FY) 2016-17. The number of individuals living in state-operated residential facilities is estimated to be 747 by the end of FY 2016-17.

Developmental Center Closures

On October 1, 2015, the Department submitted to the Legislature a plan for the closure of the Sonoma Developmental Center (Sonoma). In addition, the May Revision of the proposed 2015-16 budget announced the planned closure of the remaining developmental centers. On November 30, 2015, the Department announced its intent to submit a plan to the Legislature by April 1, 2016, for the closure of the Fairview Developmental Center (Fairview) and the Porterville Developmental Center – General Treatment Area (Porterville GTA). In light of the planned and announced closures, the Governor's Budget includes funds for both the Community Services and Developmental Centers Programs. More specifically, the Governor's Budget includes:

- \$78.8 million (\$73.9 million GF) for regional centers to develop resources in FY 2016-17 to support the transition of DC residents into the community from Sonoma, Fairview, and Porterville GTA. This is an increase of \$30.8 million (\$25.7 million GF) from the FY 2015-16 Enacted Budget.
- \$1.7 million (\$1.1 million GF) in FY 2015-16, and \$3.0 million (\$1.9 million GF) in FY 2016-17 in the Developmental Centers Budget, to begin preliminary closure activities at Sonoma. These activities include inventorying and archiving clinical and historical records, contracting for an independent monitor as stipulated in the settlement agreement with the Centers for Medicare and Medicaid Services (CMS) regarding Sonoma decertification, and relocating residents and their belongings to community settings.
- \$2.1 million (\$1.8 million GF) within Headquarters for staffing and contract resources needed to support the continued efforts for multiple developmental center closures.

As required by Senate Bill 82 (Chapter 23, Statutes of 2015) the Department included in its Developmental Center Estimate, impacts to the General Fund from closure activities.

Governor's Budget Summary

The January 2016-17 Governor's Budget includes \$6.4 billion total funds (TF) (\$3.8 billion GF) for the Department in 2016-17; a net increase of \$394.4 million above the updated 2015-16 budget, or a 6.6 percent TF increase (7.4 percent GF).

FUNDING SUMMARY (Dollars in Thousands)				
	2015-16	2016-17	Difference	Percent of Change
BUDGET SUMMARY				
Community Services	\$5,335,142 *	\$5,774,088	\$438,946	8.2%
Developmental Centers	574,160	526,037	-48,123	-8.4%
Headquarters Support	46,018	49,609	3,591	7.8%
TOTALS, ALL PROGRAMS	\$5,955,320	\$6,349,734	\$394,414	6.6%
GENERAL FUND				
Community Services	\$3,129,340 *	\$3,426,912	\$297,572	9.5%
Developmental Centers	348,778	307,481	-41,297	-11.8%
Headquarters Support	29,857	32,637	2,780	9.3%
TOTALS, ALL PROGRAMS	\$3,507,975	\$3,767,030	\$259,055	7.4%

* This amount includes \$61.5 million for prior year loan repayments, but is not reflected in the Regional Center Local Assistance Estimate totals to avoid overstating 2015-16 expenditures.

For more details, see Budget Summary and Funding Charts on pages 9-10.

COMMUNITY SERVICES PROGRAM

2015-16

To provide services and support to 290,496 individuals in the community, the Governor's Budget updates the enacted budget to \$5.3 billion TF (\$3.1 billion GF). This reflects a net decrease of \$43.4 million TF (\$68.6 million GF decrease) as compared to the enacted budget for regional center operations (OPS) and purchase of services (POS). This decrease is composed of:

Caseload and Utilization:

\$43.4 million net decrease (\$68.6 million GF decrease) in regional center OPS and POS as follows:

- OPS increase of \$1.6 million (\$2.7 million GF increase)
- POS decrease of \$45.0 million (\$71.3 million GF decrease)

The increase in OPS is due to an estimated population increase of 565 consumers over the enacted budget, whereas the decrease in POS reflects expenditure growth occurring at a slightly slower pace than previously estimated. The decrease in GF in POS is due to increased federal reimbursements and adjustments consistent with current estimating trends.

2016-17

The Governor's Budget projects a total community caseload of 302,419 consumers by January 31, 2017 – an increase of 12,488 consumers over the updated 2015-16 caseload. The estimate proposes \$5.8 billion TF (\$3.4 billion GF); a net increase of \$457 million (\$290.4 million GF) over the enacted budget. The Community Services budget changes include:

Caseload and Utilization:

\$235 million increase (\$149.2 million GF increase) in regional center OPS and POS as follows:

- OPS increase of \$22.3 million (\$16.2 million GF)
- POS increase of \$212.7 million (\$133 million GF)

The major increases in POS expenditures are within the day programs, support services, in-home respite, health care, and miscellaneous budget categories, all of which reflect updated expenditure data and consumer growth.

Compliance with New Home and Community Based Services (HCBS)

Regulations:

\$1.6 million increase (\$0.9 million GF increase) in OPS to fund an additional 21 Program Evaluator positions within the regional centers to ensure HCBS program settings are integrated into the community by March 2019, as required by the new regulations. In addition, a \$15.0 million increase (\$11.0 million GF increase) in POS to fund modifications to some service providers' programs that will be necessary for compliance with HCBS regulations by March 2019, to continue to receive federal HCBS funds.

Client Program Coordinators to Improve Caseload Ratios:

\$17 million increase (\$13 million GF increase) to fund additional regional center Service Coordinator positions to reduce caseload ratios and thereby improve case management functions.

Community Placement Plan for Developmental Center Closures:

\$30.8 million increase (\$28.3 million GF increase) to develop resources to support the transition of DC residents into the community from Sonoma, Fairview, and Porterville GTA. This includes \$4.1 million for regional center operations, and \$26.6 million to develop community living arrangements and place consumers moving from DCs. This amount is in addition to regular Community Placement Plan proposed funding of \$68 million.

Minimum Wage Increase:

\$62.4 million increase (\$35 million GF increase) in POS to fund the requirements of Assembly Bill 10 (Chapter 351, Statutes of 2013) that increased the State minimum wage from \$9.00 to \$10.00 effective January 1, 2016.

Update on Federal Labor Regulations:

\$54.2 million increase (\$29.2 million GF increase) in POS to reflect full year implementation of the Fair Labor Standards Act (FLSA) to include home care workers in overtime compensation.

Implementation of Behavioral Health Treatment (BHT) Services by Department of Health Care Services (DHCS):

\$4.5 million decrease (\$2.2 million GF decrease) in POS to reflect a reduction in expenditures for the consumers who began receiving BHT services in September 2014 from DHCS as a Medi-Cal benefit per Senate Bill 870 (Chapter 40, Statutes of 2014).

Alternative Residential Model (ARM) 4-Bed Rate Model

\$46.0 million increase (\$26.0 million GF increase) to fund ARM rates based on a four-resident model for Community Care Facilities vended to serve four or fewer individuals.

DEVELOPMENTAL CENTERS PROGRAM

2015-16

To provide services and support to 1,011 residents in developmental centers (average in-center population), the Governor's Budget updates the Enacted Budget to \$574.2 million TF (\$348.8 million GF); a net increase of \$60.2 million TF (\$55.2 million GF) for Developmental Centers' State Operations funding. Significant changes are as follows:

Various Employee Compensation and Staff Benefit Contribution Increases:

\$13.0 million increase (\$8.6 million GF increase) for 2015-16 employee compensation augmentations approved through the collective bargaining process, as well as increases in retirement and other staff benefit employer contribution rates.

Staffing Adjustments:

\$1.5 million net increase (\$.8 million GF increase) and 24.4 positions (7.8 Level of Care and 16.6 Non-Level of Care) for staffing necessary to operate developmental centers with reduced populations during the closure process, to assist with consumers moving into the community, to comply with requirements pursuant to CMS agreements and standards, and to support multiple, overlapping closure activities.

Sonoma DC Preliminary Advanced Closure Costs

\$1.7 million increase (\$1.1 million GF increase) to begin preliminary closure activities including inventorying and archiving clinical and historical records, contracting for an independent monitor as stipulated in the settlement agreement with the CMS regarding Sonoma decertification, and relocating residents and their belongings to community settings.

DC Audit Finding - Revised Expenditure Authority per Item 4300-101-0001, Provision 3

\$42.5 million GF one-time increase to repay the Department of Health Care Services as a result of audit findings, to be funded by a transfer from the Local Assistance budget in Item 4300-101-0001.

Acute Crisis Unit at Sonoma DC – Full Year Adjustment:

\$1.0 million net increase (\$1.4 million GF increase) to fund the full year costs associated with staffing the unit for a full fiscal year. The initial request made during the 2014 May Revision was limited by statute to only reflect one-half of the 2014-15 fiscal year staffing costs. This increase is necessary to fund the full fiscal year.

Key Staff Functions to be Centralized at Headquarters:

\$1.0 million decrease (\$0.8 million GF decrease) and 9.0 position reduction due to DDS revising the Enacted Budget 2015-16 assumption that identified Lanterman DC Post-Closure activities, and now requests that these and other positions throughout the DC system be transferred to Headquarters (HQ) and centralized as the department moves forward with closing multiple facilities with overlapping timelines.

Revised Budgetary Expenditure Authority for Deferred Maintenance

\$1.6 million GF increase consistent with CS 6.10 of the Budget Act, which specifies the Director of Finance may allocate funds to departments for deferred maintenance projects, and shall provide a list of projects to the Chairperson of the Joint Legislative Budget Committee. DDS' list of approved projects are all located at Porterville DC; to include \$0.4 million GF for the repair of two groundwater wells, \$0.4 million GF to upgrade the security cameras within the Secured Treatment Area, and \$0.8 million GF to re-key entire facility to a master/sub-master key schedule.

2016-17

The Governor's Budget includes funds for services and support of 847 residents (average in-center population) in the DCs; a decrease of 188 residents from the 2015-16 Enacted Budget. Total funding increased by \$12.1 million (\$14.0 million GF), and authorized positions decreased by a net of 123.8 positions, for a total of 4,125.2 authorized positions. Significant changes are as follows:

Various Employee Compensation and Staff Benefit Contribution Increases:

\$14.2 million increase (\$9.4 million GF increase) for 2015-16 employee compensation augmentations approved through the collective bargaining process, as well as increases in retirement and other staff benefit employer contribution rates.

Staffing Adjustments

\$8.8 million decrease (\$4.9 million GF decrease) and a total reduction of 129.2 positions (63.1 Level of Care and 66.1 Non-Level of Care) based on an estimated population decline of 188 DC residents transitioning into the community. The reduction reflects adjustments to staffing for specialized support and closure activities.

Sonoma DC Preliminary Advanced Closure Costs

\$3.0 million increase (\$1.9 million GF increase) to begin preliminary closure activities including inventorying and archiving clinical and historical records, contracting for an

independent monitor as stipulated in the settlement agreement with the CMS regarding Sonoma decertification, and relocating residents and their belongings to community settings.

Office of Protective Services' Records Management System:

\$0.4 million increase (\$0.3 million GF increase) to fund the acquisition of a Records Management System that will enable the Department's Office of Protective Services to efficiently and effectively report, manage, and track DC investigations, including within the Porterville DC-Secured Treatment Program (PDC-STP) and Canyon Springs Community Facility which are not slated for closure.

Developmental Centers Workers' Compensation Cases:

\$2.3 million net decrease (\$1.0 million GF increase) in appropriation from \$17.3 million (\$9.1 million GF) to \$15 million (\$10.1 million GF) to fund the settlement of remaining open permanent and stationary Workers' Compensation claims associated with current and former employees assigned to work at the various DCs and the State Operated Community Facilities. DDS requests that this \$15 million level of funding continue throughout the DC closure timeline.

Replace Personal Alarm Locating System at Porterville DC:

\$1.8 million GF increase to replace the Personal Alarm Locating System in the Porterville Developmental Center – Secure Treatment Program areas.

DC Audit Findings

\$3.8 million GF increase payable to the Department of Health Care Services for audit findings estimated to be payable in the Budget Year.

Acute Crisis Unit at Sonoma DC – Full Year Adjustment:

\$1.0 million net increase (\$1.4 million GF increase) to fund the full year costs associated with staffing the unit for a full fiscal year. The initial request made during the 2014 May Revision was limited by statute to only reflect one-half of the 2014-15 fiscal year staffing costs. This increase is necessary to fund the full fiscal year.

Key Staff Functions to be Centralized at Headquarters:

\$1.0 million decrease (\$0.8 million GF decrease) and 9.0 position reduction due to DDS revising the November 2014 assumption that identified Lanterman DC Post-Closure activities, and now requests that these and other positions throughout the DC system be transferred to HQ and centralized as the department moves forward with closing multiple facilities with overlapping timelines.

HEADQUARTERS

2015-16

The Governor's Budget reflects an increase to the 2015-16 Headquarters' enacted operations funding of \$2.2 million TF (\$1.5 million GF) for Retirement Rate Contribution, Employee Compensation, and other Staff Benefit increases, as well as the transfer of 9 positions from the Developmental Centers to Headquarters. The mid-year adjusted 2015-16 headquarters budget is \$46.0 million TF (\$29.9 million GF).

2016-17

The Governor's Budget proposes Headquarters operations funding for 2016-17 of \$49.5 million TF (\$32.6 million GF). This is a net increase of \$5.7 million TF (\$4.3 million GF) over the FY 2015-16 Enacted Budget, reflecting an incremental increase in Employee Compensation, a decrease for ProRata and SWCAP, and an increase in expenditures and positions from the following four Budget Change Proposals (BCPs):

- \$2.1 million TF (\$1.8 million GF), 8.0 new positions, and the redirection of 5.0 vacant positions for staffing and contract resources needed to support the continued efforts for the closure of the Sonoma, Fairview, and Porterville GTA. This includes overseeing the development and licensing of community facilities and consumer programs, supporting layoff activities, resolving workers' compensation claims, reconciling personnel and payroll records, and collaborating and communicating with stakeholders.
- \$0.9 million TF (\$0.6 million GF) and 7.0 positions to establish a Fiscal and Program Research Unit. The new unit will compile, research, and analyze fiscal and programmatic data in response to legislative, federal government, and stakeholder inquiries regarding regional center and developmental center programs and the provision of services to persons with developmental disabilities.
- \$0.5 million TF (\$0.3 million GF) and 4.0 positions to accommodate increased workload associated with complying with the CMS' new Home and Community-Based Services regulations. The new, comprehensive regulations create additional workload for planning, training, assessing, and reporting activities to demonstrate compliance by March 2019 in order for the State to maintain \$1.7 billion annually in federal financial participation reimbursements for Purchase of Services expenditures.
- \$1.0 million TF (\$0.7 million GF) to permanently establish and retain funding for 7.0 limited-term auditor positions in the Vendor Audit Section. The positions, originally established as limited-term in FY 2014-15, will continue to provide audit coverage and oversight of the more than \$4.6 billion in vendor payments disbursed each fiscal year.

CAPITAL OUTLAY

\$6.5 million GF increase for the construction phase of the project to upgrade the fire alarm system at the Porterville Developmental Center – Secure Treatment Program.

**DEPARTMENT OF DEVELOPMENTAL SERVICES
2015 November Estimate**

FUNDING SUMMARY

(Dollars in Thousands)

	2015-16	2016-17	Difference
BUDGET SUMMARY			
COMMUNITY SERVICES	\$5,335,142 *	\$5,774,088	\$438,946
DEVELOPMENTAL CENTERS	574,160	526,037	-48,123
HEADQUARTERS SUPPORT	46,018	49,609	3,591
TOTALS, ALL PROGRAMS	\$5,955,320	\$6,349,734	\$394,414
FUND SOURCES			
General Fund	\$3,507,975 *	\$3,767,031	\$259,056
Reimbursements: Totals All	2,388,340	2,524,007	135,667
<i>Home and Community-Based Services (HCBS) Waiver</i>	1,457,481	1,574,286	116,805
<i>Medicaid (HCBS) Waiver Administration</i>	17,792	19,515	1,723
<i>Medicaid Administration</i>	12,625	12,626	1
<i>Targeted Case Management</i>	157,513	166,753	9,240
<i>Targeted Case Management Admin.</i>	4,952	4,952	0
<i>Medi-Cal</i>	214,093	207,287	-6,806
<i>Title XX Block Grant</i>	213,421	213,421	0
<i>ICF-DD/State Plan Amendment</i>	57,072	57,072	0
<i>Quality Assurance Fees (DHCS)</i>	10,100	10,100	0
<i>1915(i) State Plan Amendment</i>	193,279	205,086	11,807
<i>Money Follows the Person</i>	9,411	11,353	1,942
<i>Race to the Top</i>	143	0	-143
<i>Early Periodic Screening Diagnostic & Treatment</i>	24,818	25,910	1,092
<i>Other</i>	15,640	15,646	6
Federal Trust Fund	54,200	54,163	-37
Lottery Education Fund	343	343	0
Program Development Fund (PDF)	3,090	2,862	-228
Mental Health Services Fund	1,222	1,178	-44
Developmental Disabilities Svs Acct	150	150	0
AVERAGE CASELOAD			
Developmental Centers	1,011	847	-164
Regional Centers	290,496	302,419	11,923
AUTHORIZED POSITIONS			
Developmental Centers	4,278.8	4,125.2	-153.6
Headquarters	397.5	416.5	19.0
* This amount includes \$61.5 million for prior year loan repayments, but is not reflected in the Regional Center Local Assistance Estimate totals to avoid overstating 2015-16 expenditures.			

DEPARTMENT OF DEVELOPMENTAL SERVICES
2015 November Estimate

(Dollars in Thousands)

	2015-16	2016-17	Difference
Community Services Program			
Regional Centers	\$5,335,142 *	\$5,774,088	\$438,946
Totals, Community Services	\$5,335,142	\$5,774,088	\$438,946
General Fund	3,129,340 *	\$3,426,912	\$297,572
Dev Disabilities PDF	2,733	2,537	-196
Developmental Disabilities Svs Acct	150	150	0
Federal Trust Fund	51,354	51,354	0
Reimbursements	2,150,825	2,292,395	141,570
Mental Health Services Fund	740	740	0
Developmental Centers Program			
Personal Services	\$433,594	\$433,594	\$0
Operating Expense & Equipment	140,566	92,443	-48,123
Staff Benefits Paid Out of Operating Expense & Equipment	0	0	0
Total, Developmental Centers	\$574,160	\$526,037	-\$48,123
General Fund	\$348,778	\$307,481	-\$41,297
Federal Trust Fund	285	285	0
Lottery Education Fund	343	343	0
Reimbursements	224,754	217,928	-6,826
Headquarters Support			
Personal Services	\$40,408	\$40,614	\$206
Operating Expense & Equipment	5,610	\$8,995	3,385
Total, Headquarters Support	\$46,018	\$49,609	\$3,591
General Fund	\$29,857	\$32,638	\$2,781
Federal Trust Fund	2,561	2,524	-37
PDF	357	325	-32
Reimbursements	12,761	13,684	923
Mental Health Services Fund	482	438	-44
Totals, All Programs	\$5,955,320	\$6,349,734	\$394,414
Total Funding			
General Fund	\$3,507,975	\$3,767,031	\$259,056
Federal Trust Fund	54,200	54,163	-37
Lottery Education Fund	343	343	0
Dev Disabilities PDF	3,090	2,862	-228
Developmental Disabilities Svs Acct	150	150	0
Reimbursements	2,388,340	2,524,007	135,667
Mental Health Services Fund	1,222	1,178	-44
Caseloads			
Developmental Centers	1,011	847	-164
Regional Centers	290,496	302,419	11,923
Authorized Positions			
Developmental Centers	4,278.8	4,125.2	-153.6
Headquarters	397.5	416.5	19.0
* This amount includes \$61.5 million for prior year loan repayments, but is not reflected in the Regional Center Local Assistance Estimate totals to avoid overstating 2015-16 expenditures.			

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: AB 1565, as introduced, Lackey. Developmental services: funding.

ISSUE: Should the Council support an across the board funding increase for the I/DD system in California?

SUMMARY: Funding for the Department of Developmental Services (DDS) has not been a priority in the state budget. Many services for individuals with developmental disabilities have been reduced and community based providers across California are being forced to cut programs and close their doors. Last year, California increased its spending by \$7 billion to make its largest budget in history, yet no additional funding was provided for DDS (Source: Author's office).

This bill attempts to broadly address the chronic underfunding of the DD system in California.

BACKGROUND/ISSUES/ANALYSIS: This bill would require the department to submit a plan to the Legislature by August 1, 2017, to ensure the sustainability, quality, and transparency of community-based services for individuals with developmental disabilities. The bill would require the department to regularly consult with stakeholders in developing the plan and would require the plan to address specified topics, including, among others, recommendations for a comprehensive approach to funding regional center operations in a sustainable and transparent manner that enables regional centers to deliver high-quality services to consumers.

Existing law requires that contracts or agreements between regional centers and service providers in which the rates between the regional center and the service provider are determined through negotiations to ensure that not more than 15% of regional center funds be spent on administrative costs, as described.

This bill would instead provide that the percentage of the funds that may be spent on administrative costs varies depending on the total value, annually, of the payments received by a service provider from all regional centers.

Existing law establishes specified rates to be paid to certain service providers and the rates to be paid for certain developmental services. Existing law requires that rates to be paid to other developmental service providers either be set by the department or negotiated between the regional center and the service provider. Existing law prohibits certain provider rate increases, but authorizes increases to those rates as necessary to adjust employee wages to meet the state minimum wage law.

This bill would increase the rates established by existing law, as specified, and would require an increase to the rates set by the department and the rates negotiated between regional centers and service providers, as specified. The bill would also require the department, when setting rates for community care facilities serving people with developmental disabilities, to ensure that the rates permit the viability of those facilities by establishing different rates for each facility size, as determined by the number of beds available, that reflect reasonable differences in the cost structure of facilities with differing numbers of beds. The bill would require the department to adopt emergency regulations implementing that provision.

Existing law requires each regional center to submit, on or before August 1 of each year, to the department and the State Council on Developmental Disabilities a program budget plan for the subsequent budget year. Existing law provides that, to the extent feasible, all funds appropriated for developmental disabilities programs be allocated to those programs by August 1 of each year and designates the department as the agency responsible for the processing, audit, and payment of funds made available to regional centers.

This bill would require the department to increase the funding paid to a regional center for the regional center's operating budget, beginning July 1, 2016, by 10% above the amount the regional center otherwise would have received under the department's core staffing formula, and, beginning July 1, 2017, by 10% above the amount the regional center otherwise would have received under the department's core staffing formula, plus a percentage equal to the percentage of any increase in the California Consumer Price Index since July 1, 2016. The bill would also require the department to increase the funding provided to a regional center to enable the regional center and the regional center's purchase-of-service vendors to fund certain costs related to minimum wage requirements. This bill would declare that it is to take effect immediately as an urgency statute.

DISCUSSION: It is no secret how underfunded the California I/DD system is. In addressing the larger problem, the ARCA publication "On the Brink of Collapse" states the following:

"Without question, relative funding levels for California's community-based developmental services system have fallen in the last two decades, with the most precipitous decline seen during the Great Recession, which began in late 2007. Many service providers are now making the difficult choice to either trim service standards and expectations or to close up shop. The balance is beginning to tip with more providers each year deciding to discontinue services and inadequate numbers of new providers willing to fill the gap. Facing similar fiscal pressures, regional centers have no

choice but to allow caseload ratios to climb above legally required levels and to spend less time proactively managing each case. Increasingly, these choices are leaving Californians with developmental disabilities without adequate services and supports to meet their needs and some without any service options at all.”

The Council is a part of the Lanterman Coalition, which advocates for a 10% across the board increase. Thus, supporting AB 1565 is consistent with that position.

RECOMMENDATION: Support AB 1565 (Lackey).

COUNCIL STRATEGIC PLAN OBJECTIVE: All.

ATTACHMENTS: AB 1565 press release.

PREPARED: Bob Giovati

Increased Funding for the Developmental Disabilities Community Introduced First Day of the New Legislative Year

Monday, January 4, 2016
George Andrews, 916-319-2036

SACRAMENTO- Last month, Assemblyman Tom Lackey, R-Palmdale, joined hundreds of advocates in Lancaster and thousands across the state in a statewide Day-of-Action to restore funding to state developmental disability programs. As the Legislature reconvenes today, Assemblyman Lackey, joined by 11 co-authors, introduced Assembly Bill 1565 that will increase funding to programs by 10%, providing a modest increase after years of painful cuts.

“The State Legislature made a promise to fund the Lanterman Act so that individuals with developmental disabilities could live an independent life,” said Assemblyman Lackey. “However, California has failed to keep this promise and this system has endured more than \$1 billion in cuts because of it. It’s time to keep our word as a state and recommit to the Lanterman Promise.”

January marks the beginning of the state budgeting process and community advocates are hopeful the Governor will grant the long-awaited funding increase when his official budget proposal is unveiled later this week.

“We cannot afford to wait another year for a funding increase as programs continue close around the state and services are cut to the bare minimum,” said Mark Melanson, President of California Supported Living Network.

Funding for the Department of Developmental Services (DDS) has not been a priority in the state budget. Many services for individuals with developmental disabilities have been reduced and community based providers across California are being forced to cut programs and close their doors. Last year, California increased its spending by \$7 billion to make its largest budget in history, yet no additional funding was provided for DDS.

The DDS community is at a breaking point and the Legislature must reverse this trend. This bill will increase funding for the DDS community across the board. It also looks forward into the future to develop a sustainable funding plan for this community, working with stakeholders to ensure the sustainability, quality, and transparency of community-based services for individuals with developmental disabilities.

Assemblyman Lackey was joined by co-authors Senator Jeff Stone, Assemblymembers Katcho Achadjian, Catharine Baker, Frank Bigelow, Rocky Chávez, Shannon Grove, Eric Linder, Brian Maienschein, Chad Mayes, Jim Patterson, and Scott Wilk.

Assemblyman Lackey proudly represents the 36th Assembly District, which contains portions of Kern, San Bernardino and Los Angeles counties, including the communities of Lancaster, Palmdale, Quartz Hill, Acton, Littlerock, Lake Los Angeles, Pearblossom, Mojave, Rosamond, California City, Phelan and Piñon Hills.

- See more at: <https://ad36.asnrc.org/press-release/14093#sthash.7M7rrBu8.dpuf>

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: S. 1719: RAISE Family Caregivers Act. (H.R. 3099)

ISSUE: A bill to provide for the establishment and maintenance of a National Family Caregiving Strategy, and for other purposes.

SUMMARY: Recognize, assist, include, support, and engage family caregivers.

Section3 –

This bill directs the Department of Health and Human Services (HHS) to develop, maintain, and periodically update a National Family Caregiving Strategy.

Section4 –

HHS shall convene a Family Caregiving Advisory Council to advise it on recognizing and supporting family caregivers.

Section5 –

This Act shall terminate on December 31, 2025.

BACKGROUND/ISSUES/ANALYSIS: Introduced by Senator Susan Collins (R-ME), Senator Tammy Baldwin (D-WI), Representative Gregg Harper (R-MS-3), and Representative Kathy Castor (D-FL-14), this legislation would implement the federal Commission on Long-Term Care's bipartisan recommendation that Congress require the development of a national strategy to support family caregivers.

The bill would create an advisory body to bring together relevant federal agencies and others from the private and public sectors to advise and make recommendations. The strategy would identify specific actions that government, communities, providers, employers, and others can take to recognize and support family caregivers and be updated annually.

According to AARP, in 2013, about 40 million family caregivers provided unpaid care valued at about \$470 billion to adults who needed help with daily activities, more than total Medicaid spending that year. According to the Caregiving in the US 2015 study

from the National Alliance for Caregiving and AARP, about 3.7 million family caregivers provide care to a child under age 18 because of a medical, behavioral, or other condition or disability. (Source: Wisconsin Health Care Association).

DISCUSSION: From the American Psychological Association: Family caregivers play a critical role in our health and long term care system by providing a significant proportion of the care for both the chronically ill and aging. Estimates suggest that there are currently over 44 million Americans age 18 and older providing unpaid assistance and support to older people and adults with disabilities who live in the community (NAC & AARP, 2004). Further, the economic value of the services that family caregivers provide is estimated at approximately \$350 billion annually (AARP, 2007).

Who Are Family Caregivers and What Services Do They Provide?

- A typical family caregiver in the U.S. is female, approximately 46 years old, has at least some college experience, and spends an average of 20 hours or more per week providing unpaid care to someone 50 or older. However, the proportion of caregivers who are men is also substantial (NAC & AARP, 2004).
- Rates of caregiving can vary somewhat by ethnicity. Among the U.S. adult population, approximately one-fifth (21%) of both the Caucasian and African-American populations are providing informal care, while a slightly lower percentage of Asian-Americans (18%) and Hispanic-Americans (16%) are family caregivers (NAC & AARP, 2004).
- Duties of caregivers are usually full time and include, but are not limited to: cooking, cleaning, bathing, medical care adherence monitoring, errand running (grocery shopping, transportation to appointments) and other activities of daily living (ADLs).
- Family caregivers who provide care for individuals with Alzheimer's disease often provide more ADL assistance than non-Alzheimer's caregivers due to the impairments of the care recipient (Alzheimer's Association, 2004).

RECOMMENDATION: Support S 1791/ H.R. 3099.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 3: Quality Assurance and Innovation.

ATTACHMENTS: Congressional Budget Office Summary, Bill Text.

PREPARED: Bob Giovati



Congressional Budget Office

Nonpartisan Analysis for the U.S. Congress

Congressional Budget Office

Nonpartisan Analysis for the U.S. Congress

S. 1719, RAISE Family Caregivers Act

December 3, 2015

Cost Estimate

As ordered reported by the Senate Committee on Health, Education, Labor, and Pensions on November 18, 2015

Summary

S. 1719 would require the Secretary of the Department of Health and Human Services, in consultation with the heads of other appropriate agencies, to establish and maintain a national strategy for family caregiving. In addition, the bill would require the Secretary to convene a Family Caregiving Advisory Council, the membership of which would consist of at least nine members who are representatives of federal departments or agencies and up to 15 members who are not. The council would meet quarterly during the first year after enactment of the bill, and at least three times in each subsequent year.

CBO estimates that implementing S. 1719 would cost \$1 million over the 2016-2020 period; such spending would be subject to the availability of appropriated funds. Those costs would stem mostly from new staff to coordinate the national strategy and support the council and from travel and per diem costs for the council.

Enacting S. 1719 would not affect direct spending or revenues; therefore, pay-as-you-go procedures do not apply. CBO estimates that enacting S. 1719 would not increase net direct spending or on-budget deficits in any of the four consecutive 10-year periods beginning in 2026.

S. 1719 contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act and would impose no costs on state, local, or tribal governments.

S. 1719

IN THE HOUSE OF REPRESENTATIVES
DECEMBER 9, 2015

Referred to the Committee on Education and the Workforce

AN ACT

To provide for the establishment and maintenance of a National Family Caregiving Strategy, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the “Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2015” or the “RAISE Family Caregivers Act”.

SEC. 2. DEFINITIONS.

In this Act:

(1) **ADVISORY COUNCIL.**—The term “Advisory Council” means the Family Caregiving Advisory Council convened under section 4.

(2) **FAMILY CAREGIVER.**—The term “family caregiver” means an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation.

(3) **SECRETARY.**—The term “Secretary” means the Secretary of Health and Human Services.

(4) STRATEGY.—The term “Strategy” means the National Family Caregiving Strategy established, maintained, and updated under section 3.

SEC. 3. NATIONAL FAMILY CAREGIVING STRATEGY.

(a) IN GENERAL.—The Secretary, in consultation with the heads of other appropriate Federal agencies, shall develop, maintain, and periodically update a National Family Caregiving Strategy.

(b) CONTENTS.—The Strategy shall identify specific actions that Federal, State, and local governments, communities, health care, long-term services and supports and other providers, employers, and others can take to recognize and support family caregivers in a manner that reflects their diverse needs, including with respect to the following:

(1) Promoting greater adoption of person- and family-centered care in all health and long-term services and supports settings, with the person receiving services and supports and the family caregiver (as appropriate) at the center of care teams.

(2) Assessment and service planning (including care transitions and coordination) involving family caregivers and care recipients.

(3) Training and other supports.

(4) Information, education, referral, and care coordination, including hospice, palliative care, and advance planning services.

(5) Respite options.

(6) Financial security.

(7) Workplace policies and supports that allow family caregivers to remain in the workforce.

(c) RESPONSIBILITIES OF THE SECRETARY.—The Secretary, in carrying out this section, shall be responsible for the following:

(1) Collecting and making publicly available information, including evidence-based or promising practices and innovative models (both domestically and internationally) regarding the provision of care by family caregivers or support for family caregivers.

(2) Coordinating Federal Government programs and activities to recognize and support family caregivers while ensuring maximum effectiveness and avoiding unnecessary duplication.

(3) Providing technical assistance, such as best practices and information sharing, to State or local efforts, as appropriate, to support family caregivers.

(4) Addressing disparities in recognizing and supporting family caregivers and meeting the needs of the diverse family caregiving population.

(5) Assessing all Federal programs regarding family caregivers, including with respect to funding levels.

(d) INITIAL STRATEGY; UPDATES.—The Secretary shall—

(1) not later than 18 months after the date of enactment of this Act, develop, publish, and submit to Congress the initial Strategy incorporating the items addressed in the Advisory Council's report in section 4(d)(2) and other priority actions for recognizing and supporting family caregivers; and

(2) not less than every 2 years, update, republish, and submit to Congress the Strategy, taking into account the most recent annual report submitted under section 4(d)(1)—

(A) to reflect new developments, challenges, opportunities, and solutions; and

(B) to assess progress in implementation of the Strategy and, based on the results of such assessment, recommend priority actions for such implementation.

(e) PROCESS FOR PUBLIC INPUT.—The Secretary shall establish a process for public input to inform the development of, and updates to, the Strategy, including a process for the public to submit recommendations to the Advisory Council and an opportunity for public comment on the proposed Strategy.

(f) NO PREEMPTION.—Nothing in this Act preempts any authority of a State or local government to recognize or support family caregivers.

SEC. 4. FAMILY CAREGIVING ADVISORY COUNCIL.

(a) CONVENING.—The Secretary shall convene a Family Caregiving Advisory Council to provide advice to the Secretary on recognizing and supporting family caregivers.

(b) MEMBERSHIP.—

(1) IN GENERAL.—The members of the Advisory Council shall consist of—

(A) the appointed members under paragraph (2); and

(B) the Federal members under paragraph (3).

(2) APPOINTED MEMBERS.—In addition to the Federal members under paragraph (3), the Secretary shall appoint not more than 15 members of the Advisory Council who are not representatives of Federal departments or agencies and who shall include at least one representative of each of the following:

(A) Family caregivers.

(B) Older adults with long-term services and supports needs, including older adults facing disparities.

(C) Individuals with disabilities.

(D) Advocates for family caregivers, older adults with long-term services and supports needs, and individuals with disabilities.

(E) Health care and social service providers.

(F) Long-term services and supports providers.

(G) Employers.

(H) Paraprofessional workers.

(I) State and local officials.

(J) Accreditation bodies.

(K) Relevant industries.

(L) Veterans.

(M) As appropriate, other experts in family caregiving.

(3) FEDERAL MEMBERS.—The Federal members of the Advisory Council, who shall be nonvoting members, shall consist of the following:

(A) The Administrator of the Centers for Medicare & Medicaid Services (or the Administrator's designee).

(B) The Administrator of the Administration for Community Living (or the Administrator's designee who has experience in both aging and disability).

(C) The Assistant Secretary for the Administration for Children and Families (or the Assistant Secretary's designee).

(D) The Secretary of Veterans Affairs (or the Secretary's designee).

(E) The Secretary of Labor (or the Secretary's designee).

(F) The Secretary of the Treasury (or the Secretary's designee).

(G) The National Coordinator for Health Information Technology (or the National Coordinator's designee).

(H) The Administrator of the Small Business Administration (or the Administrator's designee).

(I) The Chief Executive Officer of the Corporation for National and Community Service (or the Chief Executive Officer's designee).

(J) The heads of other Federal departments or agencies (or their designees), as appointed by the Secretary or the Chair of the Advisory Council.

(4) DIVERSE REPRESENTATION.—The Secretary shall ensure that the membership of the Advisory Council reflects the diversity of family caregivers and individuals receiving services and supports.

(c) MEETINGS.—The Advisory Council shall meet quarterly during the 1-year period beginning on the date of enactment of this Act and at least three times during each year thereafter. Meetings of the Advisory Council shall be open to the public.

(d) ADVISORY COUNCIL ANNUAL REPORTS.—

(1) IN GENERAL.—Not later than 12 months after the date of enactment of this Act, and annually thereafter, the Advisory Council shall submit to the Secretary and Congress a report concerning the development, maintenance, and updating of the Strategy and the implementation thereof, including a description of the outcomes of the recommendations and priorities under paragraph (2), as appropriate. Such report shall be made publicly available by the Advisory Council.

(2) INITIAL REPORT.—The Advisory Council's initial report under paragraph (1) shall include—

(A) an inventory and assessment of all federally funded efforts to recognize and support family caregivers and the outcomes of such efforts, including analyses of the extent to which federally funded efforts are reaching family caregivers and gaps in such efforts;

(B) recommendations for priority actions—

(i) to improve and better coordinate programs; and

(ii) to deliver services based on the performance, mission, and purpose of a program while eliminating redundancies and ensuring the needs of family caregivers are met;

(C) recommendations to reduce the financial impact and other challenges of caregiving on family caregivers; and

(D) an evaluation of how family caregiving impacts the Medicare program, and Medicaid program, and other Federal programs.

(e) NONAPPLICABILITY OF FACA.—The Federal Advisory Committee Act (5 U.S.C. App.) shall not apply to the Advisory Council.

SEC. 5. SUNSET PROVISION.

The authority and obligations established by this Act shall terminate on December 31, 2025.

Passed the Senate December 8, 2015.

Attest:

JULIE E. ADAMS,
Secretary

COUNCIL AGENDA ITEM DETAIL SHEET

BILL: S. 2427, Disability Integration Act (DIA).

ISSUE: Should the Council support a bill that asserts individuals with disabilities have the basic right to live independent, fulfilling lives?

SUMMARY: The Disability Integration Act of 2015 ensures services are provided to any individual who is found eligible for institutional care to receive critical services and supports in the setting of their choosing.

BACKGROUND/ISSUES/ANALYSIS: Specifically, the legislation ensures that any individual who is found eligible for institutional care must also be given the option to receive the same necessary services and supports at home, or in a setting of their choosing, that would have otherwise been provided in an institutional setting.

The Disability Integration Act ensures that any individual with a disability who is found eligible for institutional care must be given the option to receive the necessary services that allow them to be more independent. If passed, this legislation would prohibit public entities and insurance providers that pay for long-term services and supports (LTSS) from using waiting lists, screening people out, capping services, under-paying workers for services or taking any other actions that would restrict the home- and community-based services provided to people with disabilities. The Disability Integration Act specifically defines LTSS as the assistance provided to individuals with disabilities in accomplishing, acquiring the means or ability to accomplish, maintaining, or enhancing activities of daily living, instrumental activities of daily living, health-related tasks or other related functions, tasks or activities. For example, LTSS programs might include help with eating, bathing, dressing, preparing food, managing medication and housekeeping.

In addition, Schumer explained that this is an incentive-based system. States, or public entities in the state, that comply with the objectives outlined in this bill within a certain time frame could see an increase in their federal medical assistance percentage (FMAP) rate. The FMAP rate determines the federal government's share of Medicaid expenditures for a state. Full compliance with this bill would result in a five percent increase in FMAP for the state. Schumer's legislation is modeled on the principles embodied by the Americans with Disabilities Act (ADA) in order to ensure and encourage independence of disabled individuals and seniors. The ADA was signed in 1990 to ensure people with disabilities are integrated into society. The Disability Integration Act strengthens the ADA's integration mandate to ensure that "No public entity or LTSS insurance provider shall deny an individual with an LTSS disability who

is eligible for institutional placement, or otherwise discriminate against that individual in the provision of, community-based long-term services and supports that enable the individual to live in the community and lead an independent life.” Previous legislative approaches have mainly focused on the services provided by Medicaid, which is the primary payer for LTSS. Therefore, Schumer said that more must be done to protect those who want to live independently in their community.

The Disability Integration Act would require the Department of Health and Human Services (HHS) to issue regulations to clarify specifics on eligibility and minimum requirements for coverage of services and supports with which providers will need to comply. Public entities and LTSS insurance providers would be required to conduct evaluations of their current practices and policies within six months of the release of these new regulations to describe current gaps in their systems and to address how they will adapt their policies and practices to comply accordingly. Public entities would be required to present transition plans within one year after completing the evaluation to prove that they have created and begun implementation of a plan that makes the adjustments they deemed necessary in their self-evaluation. (Source: Office of Senator Charles Schumer).

DISCUSSION: Previous legislative approaches have mainly focused on the services provided by Medicaid, which is the primary payer for LTSS. Therefore, Schumer said that more must be done to protect those who want to live independently in their community. Schumer said that his Disability Integration Act addresses a long-standing civil rights problem: individuals living with disabilities are frequently denied the freedom to live independent lives in their own communities, often among family and friends. The proposed legislation would help provide necessary services and supports without requiring institutional care. Schumer said this is particularly important when considering the cost of institutional care facilities. (Source: Office of Senator Charles Schumer).

RECOMMENDATION: Support S 2427.

COUNCIL STRATEGIC PLAN OBJECTIVE: Goal 3: Quality Assurance and Innovation.

ATTACHMENTS: Bill Text.

PREPARED: Bob Giovati

S. 2427

Text of the Disability Integration Act of 2015

S. 2427

IN THE SENATE OF THE UNITED STATES

December 18, 2015

Mr. Schumer introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To prohibit discrimination against individuals with disabilities who need long-term services and supports, and for other purposes.

1.

Short title

This Act may be cited as the Disability Integration Act of 2015.

2.

Findings and purposes

(a)

Findings

Congress finds the following:

(1)

In enacting the Americans with Disabilities Act of 1990 (referred to in this Act as the ADA), Congress—

(A)

recognized that historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem; and

(B)

intended that the ADA assure full participation and independent living for individuals with disabilities by addressing discrimination against individuals with disabilities [that] persists in critical areas, including institutionalization.

(2)

While Congress expected that the ADA's integration mandate would be interpreted in a manner that ensures that individuals who are eligible for institutional placement are able to exercise a right to community-based long-term services and supports, that expectation has not been fulfilled.

(3)

The holdings of the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999), and companion cases, have clearly articulated that individuals with disabilities have a civil right under the ADA to participate in society as equal citizens. However, many States still do not provide sufficient community-based long-term services and supports to individuals with disabilities to end segregation in institutions.

(4)

The right to live in the community is necessary for the exercise of the civil rights that the ADA was intended to secure for all individuals with disabilities. The lack of adequate community-based services and supports has imperiled the civil rights of all individuals with disabilities, and has undermined the very promise of the ADA. It is, therefore, necessary to recognize in statute a robust and fully articulated right to community living.

(5)

States, with a few exceptions, continue to approach decisions regarding long-term services and supports from social welfare and budgetary perspectives, but for the promise of the ADA to be fully realized, States must approach these decisions from a civil rights perspective.

(6)

States have not consistently planned to ensure sufficient services and supports for individuals with disabilities, including those with the most significant disabilities, to enable individuals with disabilities to live in the most integrated setting. As a result, many individuals with disabilities who reside in institutions are prevented from residing in the community and individuals with disabilities who are not in institutions find themselves at risk of institutional placement.

(7)

The continuing existence of unfair and unnecessary institutionalization denies individuals with disabilities the opportunity to live and participate on an equal basis in the community and costs the United States billions of dollars in unnecessary spending related to perpetuating dependency and unnecessary confinement.

(b)

Purposes

The purposes of this Act are—

(1)

to clarify and strengthen the ADA's integration mandate in a manner that accelerates State compliance;

(2)

to clarify that every individual who is eligible for long-term services and supports has a Federally protected right to be meaningfully integrated into that individual's community and receive community-based long-term services and supports;

(3)

to ensure that States provide long-term services and supports to individuals with disabilities in a manner that allows individuals with disabilities to live in the most integrated setting, including the individual's own home, have maximum control over their services and supports, and ensure that long-term services and supports are provided in a manner that allows individuals with disabilities to lead an independent life;

(4)

to establish a comprehensive State planning requirement that includes enforceable, measurable objectives that are designed to transition individuals with all types of disabilities at all ages out of institutions and into the most integrated setting; and

(5)

to establish a requirement for clear and uniform annual public reporting by States that includes reporting about—

(A)

the number of individuals with disabilities who are served in the community and the number who are served in institutions; and

(B)

the number of individuals with disabilities who have transitioned from an institution to a community-based living situation, and the type of community-based living situation into which those individuals have transitioned.

3.

Definitions and rule

(a)

Definitions

In this Act:

(1)

Activities of daily living

The term activities of daily living has the meaning given the term in section 441.505 of title 42, Code of Federal Regulations (or a successor regulation).

(2)

Administrator

The term Administrator means—

(A)

the Administrator of the Administration for Community Living; or

(B)

another designee of the Secretary of Health and Human Services.

(3)

Community-based

The term **community-based**, when used in reference to services or supports, means services or supports that are provided to an individual with an LTSS disability to enable that individual to live in the community and lead an independent life, and that are delivered in whichever setting the individual with an LTSS disability has chosen out of the following settings with the following qualities:

(A)

In the case of a dwelling or a nonresidential setting (such as a setting in which an individual with an LTSS disability receives day services and supported employment), a dwelling or setting—

(i)

that, as a matter of infrastructure, environment, amenities, location, services, and features, is integrated into the greater community and supports, for each individual with an LTSS disability who receives services or supports at the setting—

(I)

full access to the greater community (including access to opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community); and

(II)

access to the greater community to the same extent as access to the community is enjoyed by an individual who is not receiving long-term services or supports;

(ii)

that the individual has selected as a meaningful choice from among nonresidential setting options, including nondisability-specific settings;

(iii)

in which an individual has rights to privacy, dignity, and respect, and freedom from coercion and restraint;

(iv)

that, as a matter of infrastructure, environment, amenities, location, services, and features, optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including choices about daily activities, physical environment, and persons with whom the individual interacts; and

(v)

that, as a matter of infrastructure, environment, amenities, location, services, and features, facilitates individual choice regarding the provision of services and supports, and who provides those services and supports.

(B)

In the case of a dwelling, a dwelling—

(i)

that is owned by an individual with an LTSS disability or the individual's family member;

(ii)

that is leased to the individual with an LTSS disability under an individual lease, that has lockable access and egress, and that includes living, sleeping, bathing, and cooking areas over which an individual with an LTSS disability or the individual's family member has domain and control; or

(iii)

that is a group or shared residence—

(I)

in which no more than 4 unrelated individuals with an LTSS disability reside;

(II)

for which each individual with an LTSS disability living at the residence owns, rents, or occupies the residence under a legally enforceable agreement under which the individual has, at a minimum, the same responsibilities and protections from eviction as tenants have under applicable landlord-tenant law;

(III)

in which each individual with an LTSS disability living at the residence—

(aa)

has privacy in the individual's sleeping unit, including a lockable entrance door controlled by the individual;

(bb)

shares a sleeping unit only if such individual and the individual sharing the unit choose to do so, and if individuals in the residence so choose, they also have a choice of roommates within the residence;

(cc)

has the freedom to furnish and decorate the individual's sleeping or living unit as permitted under the lease or other agreement;

(dd)

has the freedom and support to control the individual's own schedules and activities; and

(ee)

is able to have visitors of the individual's choosing at any time; and

(IV)

that is physically accessible to the individual with an LTSS disability living at the residence.

(4)

Dwelling

The term dwelling has the meaning given the term in section 802 of the Fair Housing Act (42 U.S.C. 3602).

(5)

Health-related tasks

The term health-related tasks means specific nonacute tasks, typically regulated by States as medical or nursing tasks that an individual with a disability may require to live in the community, including—

(A)

administration of medication;

(B)

assistance with use, operation, and maintenance of a ventilator;

(C)

maintenance of a catheter; and

(D)

maintenance of a stable ostomy.

(6)

Individual with a disability

The term individual with a disability means an individual who is a person with a disability, as defined in section 3 of the Americans with Disabilities Act of 1990 (42 U.S.C. 12102).

(7)

Individual with an LTSS disability

The term individual with an LTSS disability means an individual with a disability who—

(A)

in order to live in the community and lead an independent life requires assistance in accomplishing—

(i)

activities of daily living;

(ii)

instrumental activities of daily living;

(iii)

health-related tasks; or

(iv)

other functions, tasks, or activities related to an activity or task described in clause (i), (ii), or (iii); and

(B)(i)

is currently in an institutional placement; or

(ii)

is at risk of institutionalization if the individual does not receive community-based long-term services and supports.

(8)

Instrumental activities of daily living

(A)

In general

The term instrumental activities of daily living means 1 or more activities related to living independently in the community, including activities related to—

(i)

nutrition, such as preparing meals or special diets, monitoring to prevent choking or aspiration, or assisting with special utensils;

(ii)

household chores and environmental maintenance tasks;

(iii)

communication and interpersonal skills, such as—

(I)

using the telephone or other communications devices;

(II)

forming and maintaining interpersonal relationships; or

(III)

securing opportunities to participate in group support or peer-to-peer support arrangements;

(iv)

travel and community participation, such as shopping, arranging appointments, or moving around the community;

(v)

care of others, such as raising children, taking care of pets, or selecting caregivers; or

(vi)

management of personal property and personal safety, such as—

(I)

taking medication;

(II)

handling or managing money; or

(III)

responding to emergent situations or unscheduled needs requiring an immediate response.

(B)

Assistance

The term assistance used with respect to instrumental activities of daily living, includes support provided to an individual by another person due to confusion, dementia, behavioral symptoms, or mental or emotional disabilities, including support to—

(i)

help the individual identify and set goals, overcome fears, and manage transitions;

(ii)

help the individual with executive functioning, decisionmaking, and problem solving;

(iii)

provide reassurance to the individual; and

(iv)

help the individual with orientation, memory, and other activities related to independent living.

(9)

Long-term service or support

The terms long-term service or support and LTSS mean the assistance provided to an individual with a disability in accomplishing, acquiring the means or ability to accomplish, maintaining, or enhancing—

(A)

activities of daily living;

(B)

instrumental activities of daily living;

(C)

health-related tasks; or

(D)

other functions, tasks, or activities related to an activity or task described in subparagraph (A), (B), or (C).

(10)

LTSS insurance provider

The term LTSS insurance provider means a public or private entity that—

(A)

either directly provides funds for long-term services and supports; and

(B)

is engaged in commerce or in an industry or activity affecting commerce.

(11)

Public entity

(A)

In general

The term **public entity** means an entity that—

(i)

provides or funds institutional placements for individuals with LTSS disabilities; and

(ii)

is—

(I)

a State or local government; or

(II)

any department, agency, entity administering a special purpose district, or other instrumentality, of a State or local government.

(B)

Interstate commerce

For purposes of subparagraph (A), a public entity shall be considered to be a person engaged in commerce or in an industry or activity affecting commerce.

(b)

Rule of construction

Nothing in subsection (a)(2) or any other provision of this section shall be construed to preclude an individual with a disability from receiving community-based services and supports in an integrated community setting such as a grocery store, retail establishment, restaurant, bank, park, concert venue, theater, or workplace.

4.

Discrimination

(a)

In general

No public entity or LTSS insurance provider shall deny an individual with an LTSS disability who is eligible for institutional placement, or otherwise discriminate against that individual in the provision of, community-based long-term services and supports that enable the individual to live in the community and lead an independent life.

(b)

Specific prohibitions

For purposes of this Act, discrimination by a public entity or LTSS insurance provider includes—

(1)

the imposition or application of eligibility criteria or another policy that prevents or tends to prevent an individual with an LTSS disability, or any class of individuals with LTSS disabilities, from receiving a community-based long-term service or support;

(2)

the imposition or application of a policy or other mechanism, such as a service or cost cap, that prevent or tends to prevent an individual with an LTSS disability, or any class of individuals with LTSS disabilities, from receiving a community-based long-term service or support;

(3)

a failure to provide a specific community-based long-term service or support or a type of community-based long-term service or support needed for an individual with an LTSS disability, or any class of individuals with LTSS disabilities;

(4)

the imposition or application of a policy, rule, regulation, or restriction that interferes with the opportunity for an individual with an LTSS disability, or any class of individuals with LTSS disabilities, to live in the community and lead an independent life, which may include a requirement that an individual with an LTSS disability receive a service or support (such as day services or employment services) in a congregate or disability-specific setting;

(5)

the imposition or application of a waiting list or other mechanism that delays or restricts access of an individual with an LTSS disability to a community-based long-term service or support;

(6)

a failure to establish an adequate rate or other payment structure that is necessary to ensure the availability of a workforce sufficient to support an individual with an LTSS disability in living in the community and leading an independent life;

(7)

a failure to provide community-based services and supports, on an intermittent, short-term, or emergent basis, that assist an individual with an LTSS disability to live in the community and lead an independent life;

(8)

the imposition or application of a policy, such as a requirement that an individual utilize informal support, that restricts, limits, or delays the ability of an individual with an LTSS disability to secure a community-based long-term service or support to live in the community or lead an independent life;

(9)

a failure to implement a formal procedure and a mechanism to ensure that—

(A)

individuals with LTSS disabilities are offered the alternative of community-based long-term services and supports prior to institutionalization; and

(B)

if selected by an individual with an LTSS disability, the community-based long-term services and supports described in subparagraph (A) are provided;

(10)

a failure to ensure that each institutionalized individual with an LTSS disability is regularly notified of the alternative of community-based long-term services and supports and that those community-based long-term services and supports are provided if the individual with an LTSS disability selects such services and supports; and

(11)

a failure to make a reasonable modification in a policy, practice, or procedure, when such modification is necessary to allow an individual with an LTSS disability to receive a community-based long-term service or support.

(c)

Additional prohibition

For purposes of this Act, discrimination by a public entity also includes a failure to ensure that there is sufficient availability of affordable, accessible, and integrated housing to allow an individual with an LTSS disability to choose to live in the community and lead an independent life, including the availability of an option to live in housing where the receipt of LTSS is not tied to tenancy.

(d)

Construction

Nothing in this section shall be construed so as to prevent a public entity or LTSS insurance provider from providing community-based long-term services and supports at a level that is greater than the level that is required by this section.

5.

Administration

(a)

Authority and responsibility

(1)

Department of justice

The Attorney General shall—

(A)

investigate and take enforcement action for violations of this Act; and

(B)

enforce section 6(c).

(2)

Department of health and human services

The Secretary of Health and Human Services, through the Administrator, shall—

(A)

conduct studies regarding the nature and extent of institutionalization of individuals with LTSS disabilities in representative communities, including urban, suburban, and rural communities, throughout the United States;

(B)

publish and disseminate reports, recommendations, and information derived from such studies, including an annual report to Congress, specifying—

(i)

the nature and extent of progress in the United States in eliminating institutionalization for individuals with LTSS disabilities in violation of this Act and furthering the purposes of this Act;

(ii)

obstacles that remain in the effort to achieve the provision of community-based long-term services and supports for all individuals with LTSS disabilities; and

(iii)

recommendations for further legislative or executive action;

(C)

cooperate with, and provide technical assistance to, Federal, State, and local public or private agencies and organizations that are formulating or carrying out programs to prevent or eliminate institutionalization of individuals with LTSS disabilities or to promote the provision of community-based long-term services and supports;

(D)

implement educational and conciliatory activities to further the purposes of this Act; and

(E)

refer information on violations of this Act to the Attorney General for investigation and enforcement action under this Act.

(b)

Cooperation of executive departments and agencies

Each Federal agency and, in particular, each Federal agency covered by Executive Order 13217 (66 Fed. Reg. 33155; relating to community-based alternatives for individuals with disabilities), shall carry out programs and activities relating to the institutionalization of individuals with LTSS disabilities and the provision of community-based long-term services and supports for individuals with LTSS disabilities in accordance with this Act and shall cooperate with the Attorney General and the Administrator to further the purposes of this Act.

6.

Regulations

(a)

Issuance of regulations

Not later than 24 months after the date of enactment of this Act, the Attorney General and the Secretary of Health and Human Services shall issue, in accordance with section 553 of title 5, United States Code, final regulations to carry out this Act, which shall include the regulations described in subsection (b).

(b)

Required contents of regulations

(1)

Eligible recipients of service

The regulations shall require each public entity and LTSS insurance provider to offer, and, if accepted, provide community-based long-term services and supports as required under this Act to any individual with an LTSS disability who would otherwise qualify for institutional placement provided or funded by the public entity or LTSS insurance provider.

(2)

Services to be provided

The regulations issued under this section shall require each public entity and LTSS insurance provider to provide the Attorney General and the Administrator with an assurance that the public entity or LTSS insurance provider—

(A)

ensures that individuals with LTSS disabilities receive, as an alternative to institutional placement, assistance through hands-on assistance, training, cueing, and safety monitoring, including access to backup systems, with—

(i)

activities of daily living;

(ii)

instrumental activities of daily living;

(iii)

health-related tasks; or

(iv)

other functions, tasks, or activities related to an activity or task described in clause (i), (ii), or (iii);

(B)

coordinates, conducts, performs, provides, or funds discharge planning from acute, rehabilitation, and long-term facilities to promote individuals with LTSS disabilities living in the most integrated setting chosen by the individuals;

(C)

issues, conducts, performs, provides, or funds policies and programs to promote self-direction and the provision of consumer-directed services and supports for all populations of individuals with LTSS disabilities served;

(D)

issues, conducts, performs, provides, or funds policies and programs to support informal caregivers who provide services for individuals with LTSS disabilities; and

(E)

ensures that individuals with all types of LTSS disabilities are able to live in the community and lead an independent life, including ensuring that the individuals have maximum control over the services and supports that the individuals receive, choose the setting in which the individuals receive those services and supports, and exercise control and direction over their own lives to the greatest extent possible.

(3)

Public participation

(A)

Public entity

The regulations issued under this section shall require each public entity to carry out an extensive public participation process in preparing the public entity's self-evaluation under paragraph (5) and transition plan under paragraph (10).

(B)

LTSS insurance provider

The regulations issued under this section shall require each LTSS insurance provider to carry out a public participation process that involves holding a public hearing, providing an opportunity for public comment, and consulting with individuals with LTSS disabilities, in preparing the LTSS insurance provider's self-evaluation under paragraph (5).

(C)

Process

In carrying out a public participation process under subparagraph (A) or (B), a public entity or LTSS insurance provider shall ensure that the process meets the requirements of subparagraphs (A) and (C) of section 1115(d)(2) of the Social Security Act (42 U.S.C. 1315(d)(2)), except that—

(i)

the reference to at the State level shall be disregarded; and

(ii)

the reference to an application shall be considered to be a reference to the self-evaluation or plan involved.

(4)

Additional services and supports

The regulations issued under this section shall establish circumstances under which a public entity shall provide community-based long-term services and supports under this section

beyond the level of community-based long-term services and supports which would otherwise be required under this subsection.

(5)

Self-evaluation

(A)

In general

The regulations issued under this section shall require each public entity and each LTSS insurance provider, not later than 30 months after the date of enactment of this Act, to evaluate current services, policies, and practices, and the effects thereof, that do not or may not meet the requirements of this Act and, to the extent modification of any such services, policies, and practices is required to meet the requirements of this Act, make the necessary modifications. The self-evaluation shall include—

(i)

collection of baseline information, including the numbers of individuals with LTSS disabilities in various institutional and community-based settings served by the public entity or LTSS insurance provider;

(ii)

a review of community capacity, in communities served by the entity or provider, in providing community-based long-term services and supports;

(iii)

identification of improvements needed to ensure that all community-based long-term services and supports provided by the public entity or LTSS insurance provider to individuals with LTSS disabilities are comprehensive, are accessible, are not duplicative of existing (as of the date of the identification) services and supports, meet the needs of persons who are likely to require assistance in order to live, or lead a life, as described in section 4(a), and are high-quality services and supports, which may include identifying system improvements that create an option to self-direct receipt of such services and supports for all populations of such individuals served; and

(iv)

a review of funding sources for community-based long-term services and supports and an analysis of how those funding sources could be organized into a fair, coherent system that affords individuals reasonable and timely access to community-based long-term services and supports.

(B)

Public entity

A public entity, including a LTSS insurance provider that is a public entity, shall—

(i)

include in the self-evaluation described in subparagraph (A)—

(I)

an assessment of the availability of accessible, affordable transportation across the State involved and whether transportation barriers prevent individuals from receiving long-term services and supports in the most integrated setting; and

(II)

an assessment of the availability of integrated employment opportunities in the jurisdiction served by the public entity for individuals with LTSS disabilities; and

(ii)

provide the self-evaluation described in subparagraph (A) to the Attorney General and the Administrator.

(C)

LTSS insurance provider

A LTSS insurance provider shall keep the self-evaluation described in subparagraph (A) on file, and may be required to produce such self-evaluation in the event of a review, investigation, or action described in section 8.

(6)

Additional requirement for public entities

The regulations issued under this section shall require a public entity, in conjunction with the housing agencies serving the jurisdiction served by the public entity, to review and improve

community capacity, in all communities throughout the entirety of that jurisdiction, in providing affordable, accessible, and integrated housing, including an evaluation of available units, unmet need, and other identifiable barriers to the provision of that housing. In carrying out that improvement, the public entity, in conjunction with such housing agencies, shall—

(A)

ensure, and assure the Attorney General that there is, sufficient availability of affordable, accessible, and integrated housing in a setting that is not a disability-specific residential setting or a setting where services are tied to tenancy, in order to provide individuals with LTSS disabilities a meaningful choice in their housing;

(B)

in order to address the need for affordable, accessible, and integrated housing—

(i)

in the case of such a housing agency, establish relationships with State and local housing authorities; and

(ii)

in the case of the public entity, establish relationships with State and local housing agencies, including housing authorities;

(C)

establish, where needed, necessary preferences and set-asides in housing programs for individuals with LTSS disabilities who are transitioning from or avoiding institutional placement;

(D)

establish a process to fund necessary home modifications so that individuals with LTSS disabilities can live independently; and

(E)

ensure, and assure the Attorney General, that funds and programs implemented or overseen by the public entity or in the public entity's jurisdiction are targeted toward affordable, accessible, integrated housing for individuals with an LTSS disability who have the lowest income levels in the jurisdiction as a priority over any other development until capacity barriers for such housing are removed or unmet needs for such housing have been met.

(7)

Designation of responsible employee

The regulations issued under this section shall require each public entity and LTSS insurance provider to designate at least one employee to coordinate the entity's or provider's efforts to comply with and carry out the entity or provider's responsibilities under this Act, including the investigation of any complaint communicated to the entity or provider that alleges a violation of this Act. Each public entity and LTSS insurance provider shall make available to all interested individuals the name, office address, and telephone number of the employee designated pursuant to this paragraph.

(8)

Grievance procedures

The regulations issued under this section shall require public entities and LTSS insurance providers to adopt and publish grievance procedures providing for prompt and equitable resolution of complaints alleging a violation of this Act.

(9)

Provision of service by others

The regulations issued under this section shall require each public entity submitting a self-evaluation under paragraph (5) to identify, as part of the transition plan described in paragraph (10), any other entity that is, or acts as, an agent, subcontractor, or other instrumentality of the public entity with regards to a service, support, policy, or practice described in such plan or self-evaluation.

(10)

Transition plans

The regulations issued under this section shall require each public entity, not later than 42 months after the date of enactment of this Act, to submit to the Administrator, and begin implementing, a transition plan for carrying out this Act that establishes the achievement of the requirements of this Act, as soon as practicable, but in no event later than 12 years after the date of enactment of this Act. The transition plan shall—

(A)

establish measurable objectives to address the barriers to community living identified in the self-evaluation under paragraph (5);

(B)

establish specific annual targets for the transition of individuals with LTSS disabilities, and shifts in funding, from institutional settings to integrated community-based services and supports, and related programs; and

(C)

describe the manner in which the public entity has obtained or plans to obtain necessary funding and resources needed for implementation of the plan (regardless of whether the entity began carrying out the objectives of this Act prior to the date of enactment of this Act).

(11)

Annual reporting

(A)

In general

The regulations issued under this section shall establish annual reporting requirements for each public entity covered by this section.

(B)

Progress on objectives and targets

The regulations issued under this section shall require each public entity that has submitted a transition plan to submit to the Administrator an annual report on the progress the public entity has made during the previous year in meeting the measurable objectives and specific annual targets described in subparagraphs (A) and (B) of paragraph (10).

(12)

Other provisions

The regulations issued under this section shall include such other provisions and requirements as the Attorney General and the Secretary of Health and Human Services determine are necessary to carry out the objectives of this Act.

(c)

Review of transition plans

(1)

General rule

The Administrator shall review a transition plan submitted in accordance with subsection (b)(10) for the purpose of determining whether such plan meets the requirements of this Act, including the regulations issued under this section.

(2)

Disapproval

If the Administrator determines that a transition plan reviewed under this subsection fails to meet the requirements of this Act, the Administrator shall disapprove the transition plan and notify the public entity that submitted the transition plan of, and the reasons for, such disapproval.

(3)

Modification of disapproved plan

Not later than 90 days after the date of disapproval of a transition plan under this subsection, the public entity that submitted the transition plan shall modify the transition plan to meet the requirements of this section and shall submit to the Administrator, and commence implementation of, such modified transition plan.

(4)

Incentives

(A)

Determination

For 10 years after the issuance of the regulations described in subsection (a), the Secretary of Health and Human Services shall annually determine whether each State, or each other public entity in the State, is complying with the transition plan or modified transition plan the State or other public entity submitted, and obtained approval for, under this section. Notwithstanding any other provision of law, if the Secretary of Health and Human Services determines under this subparagraph that the State or other public entity is complying with the corresponding transition plan, the Secretary shall make the increase described in subparagraph (B).

(B)

Increase in FMAP

On making the determination described in subparagraph (A) for a public entity (including a State), the Secretary of Health and Human Services shall, as described in subparagraph (C), increase by 5 percentage points the FMAP for the State in which the public entity is located for amounts expended by the State for medical assistance consisting of home and community-based services furnished under the State Medicaid plan under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) or a waiver of such plan—

(i)

that—

(I)

are identified by a public entity or LTSS insurance provider under subsection (b)(5)(A)(iii);

(II)

resulted from shifts in funding identified by a public entity under subsection (b)(10)(B); or

(III)

are environmental modifications to achieve the affordable, accessible, integrated housing identified by a public entity under subsection (b)(6)(E); and

(ii)

are described by the State in a request to the Secretary of Health and Human Services for the increase.

(C)

Period of increase

The Secretary of Health and Human Services shall increase the FMAP described in subparagraph (B)—

(i)

beginning with the first quarter that begins after the date of the determination; and

(ii)

ending with the quarter in which the next annual determination under subparagraph (A) occurs.

(D)

Definitions

In this paragraph:

(i)

FMAP

The term FMAP means the Federal medical assistance percentage for a State determined under section 1905(b) of the Social Security Act (42 U.S.C. 1396d(b)) without regard to any increases in that percentage applicable under other subsections of that section or any other provision of law, including this section.

(ii)

Home and community-based services defined

The term home and community-based services means any of the following services provided under a State Medicaid plan under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.) or a waiver of such plan:

(I)

Home and community-based services provided under subsection (c), (d), or (i) of section 1915 of the Social Security Act (42 U.S.C. 1396n).

(II)

Home health care services.

(III)

Personal care services.

(IV)

Services described in section 1905(a)(26) of the Social Security Act (42 U.S.C. 1395d(a)(26)) (relating to PACE program services).

(V)

Self-directed personal assistance services provided in accordance with section 1915(j) of the Social Security Act (42 U.S.C. 1396n(j)).

(VI)

Community-based attendant services and supports provided in accordance with section 1915(k) of the Social Security Act (42 U.S.C. 1396n(k)).

(d)

Rule of construction

Nothing in subsection (b)(10) or (c) or any other provision of this Act shall be construed to modify the requirements of any other Federal law, relating to integration of individuals with disabilities into the community and enabling those individuals to live in the most integrated setting.

7.

Exemptions for religious organizations

This Act shall not prohibit a religious organization, association, or society from giving preference in providing community-based long-term services and supports to individuals of a particular religion connected with the beliefs of such organization, association, or society.

8.

Enforcement

(a)

Civil action

(1)

In general

A civil action for preventive relief, including an application for a permanent or temporary injunction, restraining order, or other order, may be instituted by an individual described in paragraph (2) in an appropriate Federal district court.

(2)

Aggrieved individual

The remedies and procedures set forth in this section are the remedies and procedures this Act provides to any individual who is being subjected to a violation of this Act, or who has reasonable grounds for believing that such individual is about to be subjected to such a violation.

(3)

Appointment of attorney; no fees, costs, or security

Upon application by the complainant described in paragraph (2) and in such circumstances as the court may determine to be just, the court may appoint an attorney for the complainant and may authorize the commencement of such civil action without the payment of fees, costs, or security.

(4)

Futile gesture not required

Nothing in this section shall require an individual with an LTSS disability to engage in a futile gesture if such person has actual notice that a public entity or LTSS insurance provider does not intend to comply with the provisions of this Act.

(b)

Damages and injunctive relief

If the court finds that a violation of this Act has occurred or is about to occur, the court may award to the complainant—

(1)

actual and punitive damages;

(2)

immediate injunctive relief to prevent institutionalization;

(3)

as the court determines to be appropriate, any permanent or temporary injunction (including an order to immediately provide or maintain community-based long-term services or supports for an individual to prevent institutionalization or further institutionalization), temporary restraining order, or other order (including an order enjoining the defendant from engaging in a practice that violates this Act or ordering such affirmative action as may be appropriate); and

(4)

in an appropriate case, injunctive relief to require the modification of a policy, practice, or procedure, or the provision of an alternative method of providing LTSS, to the extent required by this Act.

(c)

Attorney's fees; liability of United States for costs

In any action commenced pursuant to this Act, the court, in its discretion, may allow the party bringing a claim or counterclaim under this Act, other than the United States, a reasonable attorney's fee as part of the costs, and the United States shall be liable for costs to the same extent as a private person.

(d)

Enforcement by attorney general

(1)

Denial of rights

(A)

Duty to investigate

The Attorney General shall investigate alleged violations of this Act, and shall undertake periodic reviews of the compliance of public entities and LTSS insurance providers under this Act.

(B)

Potential violation

The Attorney General may commence a civil action in any appropriate Federal district court if the Attorney General has reasonable cause to believe that—

(i)

any public entity or LTSS insurance provider, including a group of public entities or LTSS insurance providers, is engaged in a pattern or practice of violations of this Act; or

(ii)

any individual, including a group, has been subjected to a violation of this Act and the violation raises an issue of general public importance.

(2)

Authority of court

In a civil action under paragraph (1)(B), the court—

(A)

may grant any equitable relief that such court considers to be appropriate, including, to the extent required by this Act—

(i)

granting temporary, preliminary, or permanent relief; and

(ii)

requiring the modification of a policy, practice, or procedure, or the provision of an alternative method of providing LTSS;

(B)

may award such other relief as the court considers to be appropriate, including damages to individuals described in subsection (a)(2), when requested by the Attorney General; and

(C)

may, to vindicate the public interest, assess a civil penalty against the public entity or LTSS insurance provider in an amount—

(i)

not exceeding \$100,000 for a first violation; and

(ii)

not exceeding \$200,000 for any subsequent violation.

(3)

Single violation

For purposes of paragraph (2)(C), in determining whether a first or subsequent violation has occurred, a determination in a single action, by judgment or settlement, that the public entity or LTSS insurance provider has engaged in more than one violation of this Act shall be counted as a single violation.

9.

Construction

For purposes of construing this Act—

(1)

section 4(b)(11) shall be construed in a manner that takes into account its similarities with section 302(b)(2)(A)(ii) of the Americans with Disabilities Act of 1990 (42 U.S.C. 12182(b)(2)(A)(ii));

(2)

the first sentence of section 6(b)(5)(A) shall be construed in a manner that takes into account its similarities with section 35.105(a) of title 28, Code of Federal Regulations (as in effect on the day before the date of enactment of this Act), or a successor regulation;

(3)

section 7 shall be construed in a manner that takes into account its similarities with section 807(a) of the Civil Rights Act of 1968 (42 U.S.C. 3607(a));

(4)

section 8(a)(2) shall be construed in a manner that takes into account its similarities with section 308(a)(1) of the Americans with Disabilities Act of 1990 (42 U.S.C. 12188(a)(1)); and

(5)

section 8(d)(1)(B) shall be construed in a manner that takes into account its similarities with section 308(b)(1)(B) of the Americans with Disabilities Act of 1990 (42 U.S.C. 12188(b)(1)(B)).



BLACK, HISPANIC CALIF. WOMEN REPORT ISSUES ACCESSING HEALTH CARE

Thursday, December 17, 2015

A disproportionate number of black and Hispanic women in California say they have a hard time finding a personal physician and paying for doctor visits, according to a report released Tuesday by the Kaiser Family Foundation, the *HealthyCal* reports.

The report was based on data from a 2012-2014 CDC survey.

Report Findings

According to the report, minority women in California were more likely to report having fair or poor health. For instance, fair or poor health was reported by:

- 13% of white women;
- 23% of black women; and
- 31% of Hispanic women (Guzik, *HealthyCal*, 12/17).

Overall, 20% of California women reported that cost concerns kept them from visiting a doctor in the past year, including:

- 16% of white women;
- 17% of black women; and
- 26% of Hispanic women.

Meanwhile, 22% of California women overall reported that they lacked a personal health care provider, including:

- 13% of white women;
- 15% of black women; and
- 35% of Hispanic women (Kaiser Family Foundation report, 12/15).

How The Lack Of Diversity In Medical Research Holds Us Back

A plea for good science.

[Erin Schumaker](#)

Healthy Living Editor, The Huffington Post

12/17/2015 12:45 pm ET

Although people of color make up nearly [40 percent of the U.S. population](#), they still [aren't adequately represented in health research](#), a study published in December in the journal PLOS Medicine reports.

There are real consequences to this lack of diversity, according to the researchers. "We've known for many decades that racial and ethnic disparities have existed for some of the worst diseases -- the most fatal and devastating diseases," lead study author Sam Oh, an associate researcher at the University of California, San Francisco, told The Huffington Post. Yet overwhelmingly, studies include mostly white men.

Two decades after President Clinton [passed the National Institutes of Health Revitalization Act](#) requiring the inclusion of women and people of color in federally funded research, loopholes in the law have helped sustain a largely homogenous pool of clinical study subjects. Currently, fewer than [2 percent](#) of the National Cancer Institutes' 10,000 clinical cancer trials have a primary focus on minorities, and fewer than [5 percent](#) of the NIH-funded respiratory research include minority study subjects at all.

The argument that recruiting women and minorities is a financial burden for what's already a cash-strapped federal agency isn't a sufficient excuse for exclusion, the study authors write. Lack of inclusion in research is expensive: Additional medical costs from minority patients' disproportionate disease burden totaled [\\$1.2 trillion](#) between 2003 and 2006, according to the International Journal of Health Services. What's

more, consistently studying mostly white, mostly male study subjects is incomplete science.

For pharmaceutical research in particular, diversity is important because genetic mutations can be prevalent in some ethnic groups and absent in others. For example, Oh said, carbamazepine prescribed for seizures and bipolar disorder is safe for most people to use -- but those of [South and East Asian descent can develop a life-threatening skin condition](#), Stevens-Johnson syndrome, due to a genetic variation.

"When we study diverse populations, we not only understand the basis of disease better, but we can discover better therapies," Oh said. "We won't make a dent in decreasing that burden until we understand the people who are most affected."

Tight budgets, homogenous researchers

It does take effort to recruit diverse study subjects.

"You need to really be considerate of the demands that are being placed on the people you are trying to recruit," Oh said. For example, if study recruiting hours are set between 9 a.m. and 5 p.m., only people who can take time off work or who don't need to work can afford to participate, he explained.

"If you're holding down a family and trying to provide by working several jobs, you're not going to prioritize taking time off to enter this study."

Limited access to care is another problem. Referrals to clinical studies often come from specialty care clinics, meaning if a person doesn't have access to specialty care, they may never be considered for a trial in the first place.

There's also just plain old inequality at play. As the journal Nature reported in November, [underrepresented minorities are less likely to receive medical research grants](#) from the NIH than white applicants, a disparity that's held consistent since 1985.

You need to really be considerate of the demands that are being placed on the people you are trying to recruit.

The NIH isn't blind to these issues, according to Michael Lauer, the agency's deputy director for extramural research. "Lauer said the black-white research grant gap is "something that we've taken very seriously," citing the NIH Office of Scientific Workforce Diversity as one example of the agency's efforts toward minority inclusion. He also pointed to significant diversity in a [large-scale blood pressure study](#) the NIH funded in September, as well as improved diversity in Phase III clinical trials, the final tests to determine whether a drug or treatment is safe and effective enough to go on the market.

Oh was also careful to note that these are complex problems, without simple solutions. One improvement would be to increase NIH funding to make it easier for researchers to recruit more diverse populations. The agency's inflation-adjusted budget has [decreased more than 20 percent since 2004](#), according to NPR.

"Everything is challenging when budgets fall," Lauer said. "I think actually that makes it all the more remarkable that our minority involvement in expensive Phase III trials has been going up over time, when budgets have been tight and have been going down." Funds or no funds, Oh's overarching emphasis isn't that every study should include all races equally, but rather that homogenous studies should be the exception, rather than the rule.

"We're trying to get this message across that the scientific community should be thinking about diversity," Oh said. "You learn things better when you have a diverse population."

Kaiser aims to recruit more minority medical students

Jason Song

When [Kaiser Permanente](#) announced Thursday that it plans to open a medical school in Southern California by 2019, executives also said they wanted to address one of medical education's biggest issues: diversity.

The company wants to recruit more minority students and teach doctors how to care for a diverse patient population, two goals medical schools throughout the country have been trying to achieve with mixed results.

Many ethnic groups are under-represented in medical schools, leading to concerns that doctors might struggle to treat some minority groups, especially Latinos, who make up about 17% of the U.S. population but only about 9% of medical students, according to the Assn. of American Medical Colleges.

By acknowledging that one of its new school's primary focuses will be on diversity, Kaiser executives are sending a key message, said James Prescott, the group's chief academic officer.

"When a school starts, it's important to understand their mission, and when Kaiser says diversity and meeting needs of community are top goals, it's powerful," Prescott said.

At the University of California medical schools, in fall 2014, 7% of students were black and 12% were Latino, according to UC statistics. Those numbers are an increase from 2010, when 4% of medical students were black and 8% were Latino.

Schools have tried to increase diversity by boosting recruitment efforts and financial aid packages.

USC has focused on spending scholarship funds to recruit "the best and the brightest, including minorities," said Carmen A. Puliafito, the dean of USC's Keck School of Medicine, where 6% of students are black and 8% are Latino.

USC also has mentoring programs with area K-12 schools and programs in which minority undergraduates can shadow doctors and conduct their own research.

Puliafito also said he thought Kaiser was well-positioned to add a medical school since the company already has hospitals and facilities.

"Kaiser already has a key resource," he said.

The company will have to invest in basic science education, he said, but "I'm sure they will handle it."

"They are a rich organization, and it makes sense they will spend money on this," Puliafito said.

Other schools have offered incentives for students who are willing to work in suburban or rural areas as a way to increase medical care in parts of the country that often lack physicians. At [UC Riverside](#), which opened a medical school in 2013, students who work in the Inland Empire area for five years practicing primary care medicine will have their tuition waived.

Medical school administrators said an additional medical school could also lead to more doctors serving similar areas.

"There's tremendous need for physicians in many parts of the state that remain medically underserved," said James Grant, UC Riverside spokesman. "There's a high demand and having another medical school in Southern California will surely help the physician shortage."



STANFORD STUDY FINDS BARRIERS TO END-OF-LIFE CARE ACROSS ETHNICITIES

Tuesday, November 24, 2015

While Asian, black and white Californians over age 50 value end-of-life care, access to such care often is hindered by several factors, regardless of ethnicity, [according to a recent study](#), *Kaiser Health News/KQED's "State of Health"* reports.

Details of Study

For the study, Stanford University researchers interviewed more than 300 California adults over age 50 about their attitudes toward end-of-life care and whether they had experienced barriers to obtaining such care for relatives or others in the area. The researchers interviewed 315 adults in:

- Fremont;
- Palo Alto;
- San Francisco;
- San Jose; and
- Walnut Creek.

The study included:

- 160 Asian individuals;
- 117 white individuals; and
- 38 black individuals.

The interviews were conducted in:

- English;
- Burmese;
- Hindi;
- Mandarin;
- Tagalog; and
- Vietnamese.

Researchers still are collecting data on Latino residents and plan to publish a separate study with the findings.

Findings

According to the study, all participants said they valued quality end-of-life care. However, about 60% said they had experienced barriers to obtaining such care, such as:

- Cultural values;
- Family conflicts;
- Financial issues; and
- Poor communication with health care providers.

A lack of financial means and access to adequate health insurance were the most notable barriers, according to the study.

There were no statistically significant differences in access to care across the ethnicities.

However, the study found that women were more likely to report barriers to care than men.

Meanwhile, participants with less education were more likely to report financial barriers, and patients with more education were more likely to report issues with provider communication (Feder Ostrov, "State of Health," *Kaiser Health News/KQED*, 11/23).

Straight Outta Compton: Lawsuit against school highlights toll of daily violence

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An unprecedented lawsuit against Compton Unified School District calls on schools to recognize "complex trauma" as a disability affecting students who have witnessed extreme violence in the community, under the American with Disabilities Act.

Five students and three teachers within CUSD joined the lawsuit brought by Public Counsel, a major public interest pro-bono law firm. Two of the students, brothers "Virgil" and "Phillip," gave interviews to CNN under fake names so they wouldn't face backlash for relaying their experiences in Compton.

They attend high school in the city, which has a murder rate five times the national average. Virgil says shootings can happen anytime.

"I still be shaky about walking in the daytime, 'cause nowadays people don't care out here," he told CNN.

"I was coming home... and this Hispanic guy had an African-American guy on his knees and he just blew his head off," Virgil said, recalling he was no older than six years old at the time. *"I was throwing up for like three hours. My momma didn't know why I was throwing up, I just told her I was sick."*

Examples like that are what the lawsuit refers to as "complex trauma," citing studies that show a child's brain will change after a severely disturbing event. The ability to focus and reason can be drastically scaled back, inviting more frustration, misbehavior, and even violent outbursts. Subsequently, the student could be pushed further away from education, toward a vicious cycle of punishment that can end behind bars, what some teachers and school officials call "the school-to-prison pipeline."

The lawsuit contends that complex trauma "limits major life activities... including 'learning, reading, concentrating, thinking, [and] communicating,'" and estimates that a quarter of CUSD's 22,000 student population have suffered such violent episodes. That's about 5,500 pupils.

"Because the student plaintiffs and the class members have experienced complex trauma, they meet the definition of 'individuals with disabilities'" under the federal Americans with Disabilities Act, the lawsuit goes on to claim.

"These children are, as a matter of brain science, not able to learn," lead attorney Marc Rosenbaum told CNN. "They are unable to get access to equal opportunity and to fight for their right to be recognized in the same way as if they didn't have teachers or books in their classrooms."

One of the Compton teachers suing the district, Armando Castro, told CNN, *"These kids sometimes overreact to the smallest things. Or they keep their heads down and get real quiet. Then I know something is wrong."*

Micah Ali, president of the CUSD school board, doesn't dispute the brain science referenced in the lawsuit, but sees the lawsuit as frivolous, telling CNN it will not *"get solutions for the students and families who are dealing with violence either at home or in the neighborhood."*

Implementing all the lawsuit demands would cripple the district's budget, Ali said. Even defending against the lawsuit could do so, he claimed.

"It would decimate the school district and adversely impact people who the individuals have filed the lawsuit are asserting they would like to help," Ali said.

The lawsuit was initiated by lawyers who then sought out the students and teachers who joined. It asks the district to train teachers and staff to identify those suffering from complex trauma, then for the district to provide them with supplementary help and resources.

"These families are in need. These families are not interested in lawyers making a tremendous amount of money on the backs of poor black and brown people," Ali said.

The school district argues that it already is helping troubled students and providing guidance for teachers, but Castro told CNN, *"We had not had that kind of training before the lawsuit appeared."*