



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

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THE PUBLIC MAY LISTEN IN BY CALLING:	1-800-839-9416
PARTICIPANT CODE:	8610332

DATE: September 21, 2015

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 SITES:

Silicon Valley-Monterey Office
2580 North First Street, Suite 240
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2029 W. Orangewood Ave
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Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in the meeting, should contact Michael Brett at 916/322-8481 or michael.brett@scdd.ca.gov. Requests must be received by 5:00 pm on September 15, 2015.

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 AUGUST 25, 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

B. Giovati

b. IHHS and CMS Updates

J. Lewis

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

B. Giovati/
N. Nieblas

d. Self-Determination

All

i) Update on Person Centered Planning

ii) Statewide SDP Committee

e. Disparity Issues

J. Lewis/All 8

8. **NEW BUSINESS**

a. HCB Stakeholder Committee/NCI Committee

N. Nieblas

b. Legislative Platform Update

N. Nieblas

c. Setting Legislative Priorities for 2016	B. Giovati	
d. Discussion Item on IDD and Law Enforcement	All	14
e. Awareness of Political Campaign Involvement	All	
9. ADJOURN	J. Lewis	

Item 5
APPROVAL OF
AUGUST 25, 2015 MINUTES



DRAFT

LPPC Committee Meeting Minutes
DATE: August 25, 2015

Attending Members

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

Members Absent

Tho Vinh Banh

Others Attending

Sonia Bingman
Nelly Nieblas
Karim Alipourfard
Michael Brett

1. CALL TO ORDER

Chairperson Janelle Lewis (FA) called the meeting to order at 10:15 a.m.

2. ESTABLISH QUORUM

A Quorum was established.

3. WELCOME/INTRODUCTIONS

Members and others introduced themselves as indicated.

4. MEMBER REPORTS

Connie Lapin (FA): Attended Special Olympics in Los Angeles.

Lisa Davidson (FA): Attended Los Angeles RAC Meeting. Offered positive comments about the SCDD Legislative Platform.

April Lopez (FA), Chairperson Lewis (FA), and David Forderer (SA): Attended the NACDD Conference in Reno. David also attended the Pacific Alliance Conference in Seattle.

Legend:
SA = Self-Advocate
FA = Family Advocate

Chairperson Lewis (FA): Discussed the upcoming stakeholder DOR call and public forum.

5. APPROVAL OF JUNE 23, 2015 MEETING MINUTES

It was moved/seconded (Lapin)(FA), (Davidson)(FA) and carried to approve the June 23, 2015 meeting minutes with corrections. (All in favor with no abstentions. See attendance list for voting members), approved.

The following corrections were suggested for the minutes:

1) Adding the words "personal belief" before the word "exemption" in the explanation of SB 277 2) Self- determination and employment first issues 3) Removal of the name of Feda, who is no longer with the Council. 4) During the member reports, some of Connie Lapin's (FA) report was left off the minutes. Mrs. Lapin (FA) discussed that herself, Aaron Carruthers (Executive Director of the State Council), and Kecia Weller (SA) (Council member and Chairperson for the Employment First Committee) attended the DC (which is now the DS) Taskforce on June 5, 2015 which discussed the budget and other matters dealing with essential service increases for the Lanterman Coalition. Mrs. Lapin (FA) discussed new housing studies called Priced Out for 2014. Also mentioned overtime/labor issue funding. And finally, the next CMS Committee is set for July 1, 2015. April Lopez (FA), committee member and Chair of the Council, asked if Mrs. Lapin (FA) could send an update on this meeting. It was asked for her to email this update to Bob Giovati, Deputy Director of Policy and Planning.

6. PUBLIC COMMENTS

No Public comment.

7. OLD BUSINESS (Standing Items)

a. Budget Update

Nelly Nieblas, staff, gave an overall budget update.

b. IHHS and CMS Updates

Chairperson Lewis (FA) discussed the recent federal appeals court ruling upholding overtime and wages for IHHS workers.

c. Federal & State Legislative Updates

The LPPC bill package was discussed, including SB 644.

d. Self- Determination

Sonya Bingaman, SCDD Sacramento Office Manager, provided a written summary of the Self-Determination Program in California and specifically, SCDD's responsibilities under this program. SCDD is responsible for selecting half of the members of each local volunteer Self-Determination Advisory Committee. The Regional Center selects the other half and the final member is the local Client's Rights Advocate from DRC. All of these committees have met at least once.

SCDD is also responsible for facilitating a Statewide Self-Determination Committee at least twice annually and collaborating with other stakeholders to provide reports to DDS and the legislature.

It was discussed that there were several reasons to begin planning the first Statewide Self-Determination Committee's meeting. A visual graph was distributed which outlined the difference between what aspects of the SDP are addressed in the Lanterman Act vs. in the SDP Waiver.

e. Disparity Issues

Chairperson Lewis (FA) Lewis shared information on a disparity model displayed at the NACDD Conference in Reno.

8. NEW BUSINESS

a. Legislative Committee Request Form Update

Janet Fernandez, staff, presented on the format, design, and use of the form.

b. Developmental Center Closure Policy Statement

The committee discussed a proposed SCDD position paper/ policy statement on the closure of the Sonoma Developmental Center.

It was moved/seconded (Forderer)(SA), (Lapin)(FA) to support the statement with minor changes, those changes being that informed choice and supported living also be included in the list of concerns. (All in favor with no abstentions. See attendance list for voting members).

c. United Cerebral Palsy Study

The UCP presentation was well received and members suggested it be added to the SCDD web site.

d. Special Session Update: AB 2x4 MCO Tax

It was moved/seconded (Davidson) (FA), Lapin (FA) to ask the Council to support this bill. (All in favor with no abstentions. See attendance list for voting members).

e. State Plan Survey

Janet Fernandez, staff, updated the committee on the status of the survey.

f. Legislative Platform Update

The committee discussed the SCDD legislative platform.

g. Discussion Item on IDD and Law Enforcement

Mrs. Fernandez gave an overview on I/DD issues as they relate to law enforcement.

h. Awareness of Political Campaign in the Media

There was a roundtable conversation about why the I/DD community is rarely mentioned or considered in political campaigns.

9. Adjournment

Meeting adjourned at 2:55 p.m.

Legend:

SA = Self-Advocate

FA = Family Advocate

Item 7e
DISPARITY ISSUES

Health and Health Care Disparities Among People with Disabilities

Silvia Yee, DREDF Staff Attorney

August 2011

“Aside from the public health issues that most racial/ethnic minorities face, minorities with disabilities experience additional disparities in health, prejudice, discrimination, economic barriers, and difficulties accessing care as a result of their disability—in effect, they face a “double burden.”¹

Snapshot of Disability and Race

As individuals and family members, we are all affected by functional and activity limitations that arise from health conditions, age, or injury at some point in our lives. The Centers for Disease Control (CDC) state that approximately 62 million (30%) Americans experience either some difficulty with “basic” movement, or cognitive, sensory, or emotional problems. About 14% of people experience “complex activity limitations” in their ability to participate in society, including maintaining a household, working, and pursuing hobbies. Rates of disability also increase with age. About 42 percent of individuals over the age of 65 report disability, compared with 18.6 percent of people who are younger.²

While disability affects people of all races, ethnicities, genders, languages, sexual orientations, and gender identities, this does not mean that impairment occurs uniformly among racial and ethnic groups. Disability is identified in differing ways among surveys, but national sources indicate that disability prevalence is highest among African Americans who report disability at 20.5 percent compared to 19.7 percent for non-Hispanic whites, 13.1 percent for Hispanics/Latinos and 12.4 percent of Asian Americans.³ Disability prevalence among American Indians and Alaskan Natives is 16.3 percent.⁴ In raw numbers, over 10.8 million non-institutionalized persons with disabilities (PWD) aged 5 and over are estimated to be members of ethnic minorities.⁵

Unique Barriers Lead to Health Disparities for People with Disabilities in Minority Populations

It is vitally important to distinguish between disability as a natural part of the human condition, and disability-related health disparities that can lead to compromised care, ill health, institutionalization, and premature death. These are not consequences that inevitably follow the simple fact of impairment. Rather, the above opening quotation refers to the many barriers that stand in the way of people with disabilities (PWD) of color having access to quality health care, including the stigma and discrimination that attach to actual or perceived differences attributed to demographic characteristics such as impairment, race, ethnicity, or LGBT status.

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GOVERNMENT AFFAIRS: 1660 L Street, NW, Suite 700 • Washington, DC 20036 | *Doing disability justice*

Disability health disparities arise from inaccessible physical environments, social assumptions and prejudices, and inflexible policies and procedures that, for example, assume that everyone must be able to independently fill out forms, undress unaided, transfer to high examination tables, and communicate in spoken English to receive standard health care services. For example, a survey of over 2,300 primary care facility sites in California between 2006 and 2010 found that only 3.6% had a wheelchair-accessible weight scale and 8.4% had a height-adjustable exam table, basic equipment that is necessary so people with a range of mobility limitations can transfer safely for examinations.⁶ Further consider that African Americans and Hispanics/Latinos over the age of 50 are more likely to have a mobility disability than similarly situated whites, and also use hospital services more often than whites.⁷ An Institute of Medicine report has already observed that there are “clear racial differences in medical service utilization rates of people with disabilities that were not explained by socioeconomic variables” and “persistent effects of race/ethnicity [in medical service utilization] could be the result of culture, class, and/or discrimination.”⁸ Equipment inaccessibility in many out-patient provider offices leads to fewer preventive tests, missed diagnoses, and delayed care,⁹ and this in turn disproportionately affects minorities that experience higher incidences of mobility disabilities.

In short, the relationship between race and disability is a complex one that needs to be freshly viewed as race and disability together may have a previously unaccounted cumulative impact on creating health disparities. Consider the following additional examples.

- 31 percent of PWD report fair or poor health in comparison to 6 percent of the general population.¹⁰ Among adults with a disability, 55.2 percent of Hispanic persons, and 46.6 percent of African Americans, report fair or poor health, as compared with 36.9 percent of whites.¹¹
- Adults with disabilities have a 400 percent elevated risk of developing Type II diabetes.¹² Diabetes is also a rapidly growing health challenge among Asian Americans and Pacific Islanders who have immigrated to the United States, affecting about 10 percent of Asian Americans, with 90-95 percent of these having type 2 diabetes.¹³ Despite the high correlation between diabetes and vision loss, printed self-care and treatment instructions in alternative formats such as Braille, large font type, CD, or audio recording, and accessible glucometers, are rarely available.
- 4.6 percent of Deaf people are infected with HIV/AIDS, four times the rate for the African-American population,¹⁴ the most at-risk racial group in the U.S. that “accounted for half of all new HIV diagnoses and just under half of new AIDS diagnoses in 2009.”¹⁵ Gay and bisexual men, another group heavily impacted by HIV/AIDS, have a 19 percent rate of infection, and 44 percent of those infected were unaware of their HIV status.¹⁶ Measures to target HIV/AIDS outreach and information to LGBT people of color who experience multiple health barriers must also consider the factor of hearing impairments on effective communication of health information.

- Adults with disabilities are three times more likely to commit suicide than peers without disabilities.¹⁷ Three out of five people with serious mental illness die 25 years earlier than other individuals, from preventable, co-occurring chronic diseases¹⁸ At the same time, African Americans with severe mental health disabilities are less likely than whites to access mental health services, more likely to drop out of treatment, more likely to receive poor-quality care, and more likely to be dissatisfied with care.¹⁹ Asian Americans and Hispanics are less than half as likely as whites to receive mental health treatment.²⁰
- People with significant vision loss experience a greater prevalence of obesity, hypertension and heart disease, and cigarette use than the general public.²¹ People who are Hispanic have higher rates of visual impairments than people who are African American, and both groups have higher rates of vision impairment than people who are white.²²
- 15 percent of PWD report not seeing a doctor due to cost in comparison to 6 percent of the general population.²³ At the same time, adults with annual household incomes of less than \$25,000 are more likely to report having a disability than adults with an annual household income equal to or greater than \$25,000.²⁴ PWD and members of racial minorities often share socio-economic characteristics and related health access barriers due to the expense of maintaining health with a disability. PWD are much more likely to experience various forms of material hardship—including food insecurity, not getting needed medical or dental care, and not being able to pay rent, mortgage, and utility bills—than people without disabilities, even after controlling for income and other characteristics.²⁵
- Among people who are deaf, women of color appear to experience the greatest health disparities and difficulty accessing appropriate health care. They tend to have lower incomes and poorer health, and to be less educated compared with white women. Among women of color, African American Deaf women appear to experience the greatest health disadvantages.²⁶

The importance of appropriately disaggregated data is also raised because the non-homogenous categories “people with disabilities” and “racial and ethnic minorities” experience different, and often surprising, specific health disparities. American Indians are 6 percent less likely to recover from traumatic brain injury than any other racial group due to unequal access to care.²⁷ People with developmental disabilities are often assumed to have greater access to care as a population that presumably visits care providers all the time, and yet this population experiences high rates of preventable health conditions such as fractures, skin conditions, obesity, poor oral health, and vision, hearing, and mental health problems.²⁸ A multinational study of 16,000 adults in 12 countries, found that 68 percent falsely believe that people with intellectual disabilities had the same or better health care as the general population.²⁹

Need for Data on Race and Disability in Health Context

It cannot be assumed that because PWD of color may need more health care services, they actually get that health care easily, or that they receive appropriate health care, especially when additional factors such as coverage limitations, physical inaccessibility and lack of policy modification, and stereotypes are at play. PWD of color or who are members of other minority groups are very likely to be encountering instances and forms of "double discrimination" that no single movement is effectively identifying or actively working to address.

While the correlations above are clear, the extent of the connections, the direction of any causative links, and the impact of multiple systemic health barriers in the lives of PWD of color are unknown because little data respecting the interaction of race and disability has been collected and/or analyzed with those connections in mind. What kind of care are African-Americans with mental health disabilities receiving? Is the older Asian immigrant recently diagnosed with diabetes given treatment instructions in both a language and a regular print format that he cannot read? Are Hispanic families enduring food insecurities to ensure a family member receives durable medical equipment items that are not covered or are limited by insurance? The disability and racial minority communities cannot accurately understand how to tackle these myriad barriers and disparities without much more information on how disability and minority cultures and stereotypes, as well as additional variables such as socio-economic status, sexual orientation, and gender coalesce around health and illness.

Disability Rights Education & Defense Fund extends special thanks to Blake Atkerson, 3rd year law student at UC Hastings College of the Law, and Priscilla Huang, Policy Director at Asian & Pacific Islander American Health Forum, for contributing to this report.

Endnotes

- ¹ HHS Advisory Committee on Minority Health, *Assuring Health Equity for Minority Persons with Disabilities: A Statement of Principles and Recommendations* (July 2011) at 11.
- ² Altman, Barbara & A. Bernstein, *Disability and Health in the United States, 2001-2005* (Hyattsville, MD: National Center for Health Statistics, 2008) at 5.
- ³ Brault, Matthew, *Americans With Disabilities: 2005*, Current Population Reports, P70-117, U.S. Census Bureau, Washington, DC, 2008. Many of the differences between the disability rates by race and Hispanic origin can be attributed to differences in the age distributions of their populations. For example, Hispanics are predominantly younger than non-Hispanic whites. [Blake - Note about Asian underreporting, or is that too specific to mental health?]
- ⁴ U.S. Census Bureau, *2009 American Community Survey*, S1810. Disability Characteristics 1 year estimates, available at http://factfinder.census.gov/servlet/STTable?_bm=y&-qr_name=ACS_2009_1YR_G00_S1810&-geo_id=01000US&-ds_name=ACS_2009_1YR_G00_&-lang=en&-format=&-CONTEXT=st.
- ⁵ *Id.* The 10.8 million figure is derived from subtracting the total number of PWD who identify as non-Hispanic or Latino white from the total number of those with a disability aged 5 and over.
- ⁶ Mudrick, N.R.; Breslin, M.L.; Yee, S.; and Liang, M. (2010). Accessibility of Primary Health Care Provider Settings for People with Disabilities: Information from Health Plan Audits [Slides]. Presented at the annual meeting of the American Public Health Association, Denver, CO, November 8.
- ⁷ Bowen, M., & González, H.. (2008). Racial/Ethnic Differences in the Relationship Between the Use of Health Care Services and Functional Disability: The Health and Retirement Study (1992-2004). *The Gerontologist*, 48(5), 659-67.
- ⁸ Institute of Medicine (IOM). 2007. *The Future of Disability in America*. Washington, DC: The National Academies Press, p. 92.
- ⁹ Healthy People 2020 has noted that PWD experience health disparities of delayed care, lower likelihood of preventative care, and higher incidence of tobacco use, obesity, and high blood pressure.
- ¹⁰ Seth Curtis and Dennis Heaphy, Disability Policy Consortium: *Disabilities and Disparities: Executive Summary* (March 2009), p. 3.
- ¹¹ Center for Disease Control Website, <http://www.cdc.gov/ncbddd/disabilityandhealth/data.html> [Accessed July 14, 2011].
- ¹² Curtis & Heaphy, p.3.
- ¹³ Asian American Diabetes Initiative, Joslin Diabetes Center, <http://aadi.joslin.org/content/asian/why-are-asians-higher-risk-diabetes>] (2010).
- ¹⁴ Curtis & Heaphy, p. 8.
- ¹⁵ Avert, United States Statistics by Race and Age, <http://www.avert.org/usa-race-age.htm>] (2009).
- ¹⁶ Centers for Disease Control and Prevention. (CDC) HIV and AIDS among gay and bisexual men, September 2010, available at: <http://www.cdc.gov/nchstp/newsroom/docs/FastFacts-MSM-FINAL508COMP.pdf>.
- ¹⁷ Curtis & Heaphy, p. 3.

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- ¹⁸ Assoc. of University Centers on Disabilities, "Letter to Kathleen Sebelius"
http://www.aucd.org/docs/policy/health_care/CLAS_StandardsDisabilityLetter%201-2011.pdf. Citing (Colton & Manderscheid, 2006; Manderscheid, Druss, & Freeman, 2007).
- ¹⁹ Whitley, R., & Lawson, W.. (2010). The Psychiatric Rehabilitation of African Americans With Severe Mental Illness. *Psychiatric Services*, 61(5), 508-11.
- ²⁰ 2008 National Healthcare Disparities Report. Table 15_3_1.1a & 15_3_1.1b
<http://www.ahrq.gov/qual/qdr08/index.html>
- ²¹ Michele Capella-McDonnall, "The Need for Health Promotion for Adults Who Are Visually Impaired," *Journal of Visual Impairment and Blindness* 101, no. 3 (March 2007).
- ²² *Id.* Note that a vision impairment is a visual disability not correctable by glasses or other modifications.
- ²³ Curtis & Heaphy, p. 3.
- ²⁴ Curtis & Heaphy, p. 3.
- ²⁵ Shawn Fremsted, "Half in Ten: Why Taking Disability into Account is Essential to Reducing Income Poverty and Expanding Economic Inclusion," Center for Economic and Policy Research, (2009), p. 2.
- ²⁶ National Council on Disability, The Current State of Health Care for People with Disabilities, September 30, 2009.
- ²⁷ Whitfield, H., & Lloyd, R. (2008). American Indians/Native Alaskans With Traumatic Brain Injury: Examining the Impairments of Traumatic Brain Injury, Disparities in Service Provision, and Employment Outcomes. *Rehabilitation Counseling Bulletin*, 51(3), 190-192.
- ²⁸ Special Olympics Resource Sheet on Disability Disparities, available at http://resources.specialolympics.org/research-toolkit/Health_Disparities.aspx.
- ²⁹ Special Olympics citation.

Item 8d

**DISCUSSION ITEM ON IDD
AND LAW ENFORCEMENT**

“Ethan Saylor Bill” Signed Into Law

WUSA 2:23 a.m. EDT May 13, 2015

FREDERICK, Md. (WUSA9) -- The state of Maryland took a big step forward for people with intellectual and developmental disabilities on Tuesday.

Governor Larry Hogan signed a bill that turns up the volume for the voices of people with intellectual and developmental disabilities by mandating that self-advocates become involved in the training of police officers.

For more than two years, Patti Saylor of Frederick, Maryland has been channeling her pain into fueling change. Patti Saylor says it was done in her son Ethan's honor, "This will be the Ethan Saylor alliance for self-advocates as educators and its essence is to recognize that people with intellectual and developmental disabilities should be at the table for anything we discuss."

It was January 2013, when Ethan died in police custody after being removed from a movie theater by three off-duty Frederick County Sheriff's deputies moonlighting as security, for not having a \$12 movie ticket.

The Medical Examiner ruled Ethan's death a homicide by asphyxiation. A grand jury found no wrongdoing on the part of those deputies.

Patti Saylor's fight for justice and police training has included a civil lawsuit, petitions and the appointment of the first-ever Commission for the Effective Inclusion of Individuals with Intellectual and Developmental Disabilities. Now the people she's fighting for will be able to help train police and have a voice.

Law enforcement training has already started in the state with all new recruits. Now, Patti Saylor hopes self-advocates from the intellectual and developmental disability community will be involved in that training.

"Self advocates have a voice and we need to listen to them. It's their life," Patti Saylor said.

The bill signed goes into effect July 1st, Maryland is the only state in the country that has such a bill.

Department of Legislative Services
 Maryland General Assembly
 2015 Session

FISCAL AND POLICY NOTE

Revised

Senate Bill 853

(Senator Young, et al.)

Finance

Health and Government Operations

Ethan Saylor Alliance for Self-Advocates as Educators

This bill establishes the Ethan Saylor Alliance for Self-Advocates as Educators within the Department of Disabilities (MDOD). The purpose of the alliance is to advance the “community inclusion” of individuals with intellectual disabilities and developmental disabilities by preparing and supporting self-advocates to play a central role in educating others, particularly law enforcement, about appropriate and effective interactions with individuals with intellectual disabilities and developmental disabilities.

The bill takes effect July 1, 2015.

Fiscal Summary

State Effect: General fund expenditures increase by \$75,000 in FY 2016 for MDOD to establish and fulfill the purpose of the alliance. Future year expenditures assume continued funding of the alliance through MDOD, with no expansion of the scope of the alliance, and reflect inflation. Revenues are not affected.

(in dollars)	FY 2016	FY 2017	FY 2018	FY 2019	FY 2020
Revenues	\$0	\$0	\$0	\$0	\$0
GF Expenditure	75,000	75,800	76,500	77,300	78,000
Net Effect	(\$75,000)	(\$75,800)	(\$76,500)	(\$77,300)	(\$78,000)

Note:() = decrease; GF = general funds; FF = federal funds; SF = special funds; - = indeterminate effect

Local Effect: None.

Small Business Effect: None.

Analysis

Bill Summary: The bill defines “community inclusion” as circumstances in which individuals with intellectual disabilities and developmental disabilities are welcomed, supported, and included in all aspects of society.

Ethan Saylor Alliance for Self-Advocates as Educators

The alliance must be guided by a steering committee and is to build on the work of the Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities by prioritizing the training of law enforcement officers. The alliance must connect law enforcement trainers with self-advocate educators or entities that use self-advocate educators in a central role when providing training. The alliance must also identify and support the development of self-advocate educators, identify resources needed to prepare and support self-advocate educators, and promote collaborative efforts that support community inclusion.

Steering Committee

The alliance’s steering committee consists of 13 members including 4 State officials or their designees; 3 representatives of specified organizations; 2 representatives of community-based organizations that support people with intellectual disabilities and developmental disabilities; and 4 members of the public with knowledge of intellectual disabilities and developmental disabilities, including at least 2 self-advocates and a family member of an individual with an intellectual disability or developmental disability, each appointed by the Secretary for Developmental Disabilities.

Committee members appointed by the Secretary serve for three-year terms and continue to serve until a successor is appointed and qualifies. A member may be reappointed.

Members may not receive compensation but are entitled to reimbursement for expenses under standard State travel regulations.

The steering committee is required to (1) develop parameters for the alliance, including expected outcomes and methods of evaluation; (2) select entities to operate the alliance through a competitive process; (3) provide general oversight; (4) approve the budget; (5) review the alliance’s activities and outcomes; and (6) develop recommendations for the sustainability and expansion of the alliance, including the costs of sustaining and expanding the alliance, potential sources of funding, and compensation and supports for self-advocate educators.

Funding

The alliance is to be supported by appropriations made in the annual State budget; any grants or other assistance from federal, State, or local government; and any other grants or donations to the alliance. The operation of the alliance is subject to the limitations of the State budget.

Current Law/Background: Self-advocates are people with intellectual disabilities or developmental disabilities who communicate their own interests and rights.

Though no existing State entity is tasked with addressing the issues addressed by the alliance, other State agencies, boards, commissions, and committees have been established to address, among other things, the needs of individuals with intellectual disabilities or developmental disabilities. MDOD evaluates programs and services for Maryland citizens with disabilities, coordinates and supports public and private agencies serving people with disabilities, provides information and referrals, and identifies and recommends ways to improve services. The Interagency Disabilities Board was established to develop the State Disabilities Plan. The State Disabilities Plan must address, among other specified elements, the coordination of support services that address the improvement of communities' capacity to support individuals with disabilities with personal attendant care and other self-directed long-term care options. The Maryland Commission on Disabilities advises MDOD, reviews statewide programs for persons with disabilities, and fosters coordination and support for these programs. The Personal Assistance Services Advisory Committee advises MDOD on personal care, attendant care, and home care services.

In September 2013, Governor O'Malley established, by executive order, the Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities in part as a response to the death of Maryland resident Ethan Saylor. Robert Ethan Saylor, who had Down's Syndrome, died January 12, 2013, at the age of 26 after an altercation with off-duty Frederick County sheriff's deputies in a movie theater.

The commission was tasked with (1) developing and issuing recommendations about the types of policies, guidelines, or best practices that Maryland should adopt regarding law enforcement officials, paramedics, and other first-responders' responses to situations involving individuals with intellectual and developmental disabilities; (2) developing and issuing recommendations about the types of statewide training standards that Maryland should adopt to educate individuals in positions of authority about the best approaches for safely managing situations involving individuals with intellectual and developmental disabilities; and (3) developing a coordinated, collaborative and comprehensive strategy for State and local officials, disabilities advocates, and other interested parties to ensure enhanced responses to situations involving individuals with intellectual and developmental disabilities as well as other related matters as necessary.

The commission submitted its report on December 3, 2014, which included four recommendations. Among them, the commission recommended that the State establish a new center to support the coordination and preparation of self-advocates who can become active educators in training programs in various sectors across the State. The commission recommended that the new center be an independent unit of State government, housed at a university, with a governing board that includes stakeholders from within and outside the government. The commission recommended further that the governing board develop an implementation plan, provide oversight, and establish the budget. This bill implements, in a modified form, some of the commission's recommendations.

The commission also recommended that the center be named in honor of Ethan Saylor and that the functions of the center include but not be limited to:

- working with existing disability organizations to identify individuals with intellectual and developmental disabilities who would like to be trainers and have a certain set of core skills;
- arranging for people with intellectual and developmental disabilities to participate in existing training programs;
- providing the necessary training and support for people with intellectual and developmental disabilities to meaningfully participate as trainers;
- providing coordinating support services for self-advocates, including transportation, support staff, payment of expenses and compensation for training activities; and
- identifying best practices for training on how to interact with individuals with intellectual and developmental disabilities.

State Expenditures: General fund expenditures increase by \$75,000 in fiscal 2016, which accounts for the bill's July 1, 2015 effective date. The estimate includes \$5,175 to cover the anticipated cost of supporting steering committee meetings, which are expected to require the creation of accessible meeting documents, as well as other costs associated with the needs of committee members, such as reimbursements for members who use specialty disability transportation services. The estimate includes \$69,825 for contractual services to select entities, through a competitive process, to operate and fulfill the purpose of the alliance, including to train self-advocate educators and to evaluate the results.

Contractual Services	\$69,825
Committee Reimbursement/Meeting Costs	<u>5,175</u>
Total FY 2016 State Expenditures	\$75,000

Future year expenditures assume ongoing use of State funds to support the alliance and reflect ongoing use of contractual services, committee reimbursement and related meeting costs, and inflation. However, any costs related to the expansion of the alliance have not been factored into future year estimates.

Additional Information

Prior Introductions: None.

Cross File: None.

Information Source(s): Department of Disabilities; Commission for Effective Inclusion of Individuals with Intellectual and Developmental Disabilities; Department of Business and Economic Development; Department of Budget and Management; Department of Human Resources; Maryland State Department of Education; Maryland Institute for Emergency Medical Services Systems; Governor's Office; Maryland Higher Education Commission; Department of Health and Mental Hygiene; Judiciary (Administrative Office of the Courts); Department of Labor, Licensing, and Regulation; Department of State Police; Office of the Public Defender; Department of Public Safety and Correctional Services; University System of Maryland; Department of Legislative Services

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