



**LEGISLATION AND PUBLIC POLICY COMMITTEE (LPPC)
MEETING NOTICE/AGENDA**
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PARTICIPANT CODE:	8610332

DATE: November 10, 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 SITE(S):

Silicon Valley-Monterey Office
2580 North First Street, Suite 240
San Jose, CA 95131
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520 East Montecito Street
Santa Barbara, CA 93103-3278
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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 October 13, 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 SEPTEMBER 21, 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/CMS Updates/Overtime Discussion | D. Forderer/
All | 10 |
| c. Federal & State Legislation Updates/Council Update on LPPC Bill Package & Other Bills | B. Giovati/
N. Nieblas | 14 |
| d. Self-Determination | All | |
| i) Update on Person Centered Planning | | |
| ii) Statewide SDP Committee | | |

8. **NEW BUSINESS**

- | | | |
|---|--------------|----|
| a. State Plan Goals/Legislative Priorities 2016 | J. Lewis/All | 17 |
| b. Press Outreach | N. Nieblas | |

c. Civic Activities

N. Bocanegra/
T.V. Banh

9. ADJOURN

J. Lewis

**5. APPROVAL OF
SEPTEMBER 21, 2015
MINUTES**



DRAFT

LPPC Committee Meeting Minutes

DATE: September 21, 2015

Attending Members

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

Members Absent

Others Attending

Nelly Nieblas
Bob Giovati
Michel Brett
Wayne Glusker

1. CALL TO ORDER

Chairperson Janelle Lewis (SA) 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

Members, Tho Vinh Banh and Dr. Sandra Aldana (SA), did not have a report to give.

Connie Lapin (FA):

1- Informed the members of the February 18 and 19, 2016 Conference in Los Angeles entitled: Preparing for Dramatic Changes in DD Community-Supported Decision Making.

Legend:
SA = Self-Advocate
FA = Family Advocate

- 2- Spoke about the book entitled *Neuro-Tribes: Legacy of Autism: The Legacy of Autism and the future of Neurodiversity*.
- 3- Discussed an educational center in Massachusetts that used shock therapy and now has an operation in CA.
- 4- Discussed a California lawsuit attempting to declare an autistic boy a public nuisance. The case is still currently active at this time.

Lisa Davidson (FA): Talked about a student with special needs that died after being left alone on a school bus in Southern California. The idea of sponsoring legislation to prevent such incidents was discussed. The consensus was that legislation was unnecessary. Simply thoroughly checking the bus for remaining passengers should suffice.

Dr. April Lopez (FA): Suggested the State Council make a statement about the incident.

Chairperson Lewis (FA): Mentioned that in a similar case, involving her son, a substitute bus driver took a different route than usual, causing her son emotional trauma.

- Deputy Director of Policy and Planning, Bob Giovati, stated he felt this was a possible opportunity to do a press release. He added that SCDD had been formulating a broader media strategy, which included creating a press release template. Legislation and Communications Manager, Nelly Nieblas, is currently working on the project
- Regarding the above referenced incident, Dr. Lopez (FA) said she does not want the State Council to miss the opportunity to comment on the issue. She mentioned that she has access to a media contact list for the Orange County area. She added that all SCDD regional offices have their own list of local media connections that staff could collect. Ms. Nieblas said she would also call SCDD regional offices to obtain their lists and create a master list.

Chairperson Lewis (FA) also gave an additional report regarding problems that still exist in accessing behavioral health treatment services and early autism treatment. Families trying to obtain services are extremely disappointed because services are not yet available.

David Forderer (SA): Mentioned that he met with the Santa Fe Human Right Commission consisting of Human Trafficking, Sexual Abuse, and Disability divisions.

5. APPROVAL OF THE AUGUST 25, 2015 MEETING MINUTES

It was moved/seconded (Lapin)(FA), (Aldana)(SA) and carried to approve the August 25, 2015 meeting minutes with corrections and one abstention from Bahn. (All in favor. See attendance list for voting members)

The following minute corrections need to take place: Deputy Director Bob Giovati and Tho Vinh Banh need to be removed from the attendance list. Ms. Bahn needs to be placed under members absent and Deputy Giovati needs to be completely removed.

6. PUBLIC COMMENTS

No Public comment.

7. OLD BUSINESS (Standing Items)

a. Budget Update/Special Session

Deputy Director Giovati discussed the legislative special session and the conference committee process. Although he cautioned the situation was fluid and subject to change, he felt it was unlikely anything would happen anytime soon with special session bills or with the conference committees.

Ms. Davidson (FA) stated that it was heart breaking our DD population is facing all these funding difficulties and constantly swimming upstream.

Mr. Forderer (SA) expressed concerns that with the closing of developmental centers, the money is not going to be allotted directly to people with disabilities. Therefore, we should develop strategies to secure funding for our population as a result of savings from the developmental center closures.

Dr. Sandra Aldana (SA) noted that even if obtained, money would not be available until 2017, and thus, more practical steps should be considered.

Mrs. Bahn noted that the Lanterman Coalition might be a viable source of assistance.

b. IHHs and CMS Updates

Item not discussed.

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

Deputy Director Giovati stated this committee started with an ambitious list of bills compared to last year. Out of the 23 bills SCDD officially supported in 2015, 15 are either already law, or on their way to the governor. He said SCDD should be very proud of that success record. With the foundation laid, next year's legislative accomplishments should be even greater. He also said SCDD had substantially elevated its professional profile and reputation at the Capitol.

d. Self-Determination

Update on Person Centered Planning (PCP)

Mrs. Lapin (FA) started the discussion on PCP by emphasizing that it is not the same thing as an IPP. Her concern was that regional centers may say it is when it is not. She added that PCP is an ongoing, problem-solving process used to help people with disabilities to plan for their future. In PCP, groups of people focus on an individual and that person's vision of what they would like to do in the future.

I. Statewide Self Determination Program

Self Determination relates to the Lanterman Act and its implementation through statewide regional centers and local advisory committees.

e. Disparity Issues

In general, it was stated that Council member attendance at the National Association Council of Developmental Disabilities Council

(NACDD) conference in Sparks, NV enabled them to learn and discuss developmental disability issues of national importance.

The LPPC has been informed that the State Plan Committee has collected over 1,000 responses to their State Plan survey in English but only 13 in Spanish. The State Plan Committee is considering different methodologies in distributing surveys and collecting responses.

8. NEW BUSINESS

a. HCB Stakeholder NCI Committee

Chairperson Lewis (FA) asked Ms. Nieblas, staff, to update the committee about her involvement in the HCB Stakeholder and the NCI Committee. Ms. Nieblas stated that she had been actively involved and plans to participate in their upcoming October 27, 2015 meeting. She added that she solicited Dr. Aldana's (SA) help in providing her with survey results. Dr. Aldana (SA) stated that researchers from all over the United States would be solicited to provide comparative results.

b. Legislative Platform Update

Ms. Nieblas reported the SCDD Legislative Platform has indeed been finalized, and the word "draft" has been removed. The final platform is on the SCDD website and copies will be also distributed to various offices and agencies.

c. Setting Legislative Priorities for 2016

Chairperson Lewis (SA) said the LPPC was looking at various legislative issues for the upcoming year, such; as employment, housing, and transportation.

d. Discussion Items on IDD and Law Enforcement

Deputy Director Giovati spoke about an incident that occurred in another state, where a person with I/DD died during an encounter with security officers. This resulted in a law being passed in that state requiring self-advocates be involved in police officer training. Committee discussed the idea of advocating for a similar law in CA.

e. Awareness of Political Campaign Involvement

This discussion was postponed until SCDD Legal Counsel, Natalie Bocanegra, could address the group directly.

9. ADJOURN

Meeting adjourned at 2:55 p.m. with the next meeting set for October 19, 2015

**7b. IHHS/CMS
UPDATES/OVERTIME
DISCUSSION**

Home healthcare employers brace for 'new' wage and hour rules

Jay Starkman, Contributing Writer

Sep 3, 2015, 12:01pm EDT

A recent ruling from a federal appellate court has breathed new life into Department of Labor (DOL) regulations that are poised to bring significant change to the way in which direct care workers must be paid.

The ruling essentially reinstates 2013 DOL regulations providing that direct care workers employed by third parties (such as home health or hospice agencies) no longer qualify for exemptions from the minimum wage and overtime provisions of the federal Fair Labor Standards Act (FLSA).

The decision overturns a January 2015 ruling by a lower court and holds that the DOL has the authority to extend the minimum wage and overtime protections to these workers.

What types of employees are considered direct care workers?

- Home health aides, personal care aides, caregivers, companions and/or other workers employed by a third party, including agencies
- Registered nurses, licensed practical nurses, certified nursing assistants, and/or other workers who provide medically related services, which typically require and are performed by trained medical personnel. (Note that some nurses may be covered by other FLSA exemptions)
- Workers who provide domestic services that primarily benefit other members of the household
- Workers who spend more than 20 percent of their time assisting with activities of daily living

How the ruling impacts employers

Under the “new” regulations, employers generally will need to classify their direct care employees as non-exempt. This means that most direct care workers must now be:

- Paid on an hourly basis for all hours worked
- Paid a minimum wage (local, state or federal – whichever is highest)

- Paid overtime for all time over 40 hours in a particular workweek (generally, time and one-half, but state or local rates may be higher). Some states also have additional criteria for overtime, including daily overtime.

In addition, under the regulations, “companionship services” have been redefined as: “[T]he provision of fellowship and protection for an elderly person or a person with an illness, injury or disability who requires assistance in caring for himself or herself.”

Employers should take note that an individual who spends more than 20 percent of the workweek providing “companionship services” will not qualify for the companionship exemption.

Timing and next steps for employers

Unfortunately, it is unclear when the DOL will begin enforcement of the new regulations. Initially, the regulations were set to take effect on Jan. 1, 2015, with enforcement slated to begin on July 1, 2015. The DOL has not indicated whether it will provide employers with a similar window to ease into compliance, and may ultimately take the position that employers should have been prepared for the change by now.

Home health agencies and other employers of these types of workers should consider treating impacted employees as non-exempt as soon as possible to ensure compliance.

Ryan Hollander, assistant general counsel of Engage PEO, contributed to this article.

- Disability Scoop - <http://www.disabilityscoop.com> -

Long-Delayed Caregiver Wage Protections To Take Effect

By Michelle Diamant | October 7, 2015

U.S. Supreme Court Chief Justice John Roberts denied a request from industry groups who wanted a new rule establishing minimum wage and overtime protections for home care workers to be delayed. (Larry Downing/Reuters/TNS)

The U.S. Supreme Court has paved the way for an Obama administration rule mandating minimum wage and overtime for in-home caregivers assisting those with disabilities to be implemented.

Chief Justice John Roberts issued an order Tuesday denying a request from industry groups who sought to delay the new rule.

Under the [2013 rule](#) from the U.S. Department of Labor, most home care workers must be paid at least the federal minimum of \$7.25 per hour and earn time-and-a-half for working more than 40 hours per week.

Previously, under a law dating to the 1970s, caregivers were classified similarly to baby sitters and were not entitled to the same rights as other types of employees.

Trade groups representing agencies that employ many home care workers sued over the changes arguing that the pay hike would make such care unaffordable.

Initially, the new requirements were set to take effect in January, but they were put on hold when a federal judge [ruled](#) that the Labor Department had overstepped its authority. On appeal, however, a three-judge panel [sided](#) with the Obama administration.

Last month, the groups challenging the rule asked the Supreme Court to postpone implementation of the changes so that they could further appeal the decision. With Roberts' order Tuesday, however, the rule is set to take effect Oct. 13.

"We are pleased with today's order," U.S. Secretary of Labor Tom Perez said late Tuesday. "The final rule is not only legally sound; it was the right thing to do. It will ensure fair wages for the nearly 2 million home care workers who provide critical services, and it will help ensure a stable and professional workforce for people who need those services."

The Labor Department said it will not begin enforcement of the new rule until Nov. 12 and will use "[prosecutorial discretion](#)" through the end of the year to assess whether to bring enforcement actions based on how much effort states and other relevant entities have put toward ensuring compliance.

**7c. FEDERAL & STATE
LEGISLATION
UPDATES/COUNCIL
UPDATE ON LPPC BILL
PACKAGE & OTHER BILLS**

'Right-to-die' act hangs in limbo amid special sessions' inaction

Gov. Jerry Brown signed legislation on Oct. 5 allowing terminally ill patients to legally end their lives using doctor-prescribed drugs.

That ballyhooed new California law allowing terminally ill patients to end their suffering by swallowing a lethal pill won't take effect any time soon. And nobody knows when it will.

Conceivably, it might not be until late next year — or even 2017.

First, the Legislature must adjourn its special session on healthcare financing. Then 90 days later, the "right to die" act can become real.

You probably haven't been paying much attention to the Legislature's special session. Don't feel guilty. Neither has the Legislature.

The lawmakers have pretty much checked out of Sacramento for the year and aren't scheduled to return until Jan. 4, although they're still ostensibly convened in two special sessions.

Gov. Jerry Brown called both in June, trying to kick lawmakers into gear on raising more money to fix crumbling highways and creating a new financing scheme for Medi-Cal, the state's healthcare program for the poor. Neither session is producing anything.

A few lawmakers are trying to grapple with how to raise taxes for road repairs. But the healthcare session is lifeless.

Tell you who probably is paying attention to the healthcare inaction: some terminally ill people and their loved ones. They're wondering when this façade of a session is ever going to end so they can start making plans for a dignified death.

The law's effective date is nowhere in sight. It might not be until Nov. 29, 2016 — even March 1, 2017.

Ironically, a legislative procedure that expedited passage of the right-to-die bill wound up delaying its implementation.

Brown called the special sessions to cut corners on passing the highway and healthcare bills. Votes can be taken much quicker than in a regular session.

The governor's healthcare problem is that the Obama administration has ordered California to stop part of its Medi-Cal financing by July 1. Unless the state finds replacement revenue, there'll be a \$1.1-billion budget hole in the next fiscal year.

Sacramento has been taxing Medi-Cal managed care plans. The feds say the taxing can't be limited just to Medi-Cal. Brown has proposed also taxing non-Medi-Cal plans. But these plans naturally object. It's complicated, but this is the sticking point: The Medi-Cal plans get reimbursed for their taxes — half from the state, half from the feds. The non-Medi-Cal plans wouldn't get any reimbursement.

While the governor, lawmakers and special interests were chewing over that can of worms during the summer, sponsors of the right-to-die bill seized an opportunity. Their proposal was being blocked in the regular-session Assembly Health Committee by Democrats feeling pressure from the Catholic Church.

So sponsors inserted their proposal into the special healthcare session, where the committee had friendlier members. The rest is history.

If the bill had passed in the regular session, it would be taking effect Jan. 1. Now, it's just a piece of paper floating in limbo.

"From a human perspective, I wish we could shut down this special session immediately," says Sen. Lois Wolk (D-Davis), one of the bill's authors. "We could open another."

But that would require bringing lawmakers back to Sacramento to terminate the session. "People are pretty scattered to the four corners of the planet," Wolk says.

It's called junketing.

The predominant thinking — when anyone thinks about it — is that the special session will linger inactive until at least January. Then the lawmakers — Democrats, anyway — might get inspired to act, because the governor will be proposing a new budget that contains deep Medi-Cal cuts to make up for the looming \$1.1-billion loss.

Any tax hike would require a two-thirds vote, however, and that means Republican help. But Republicans aren't likely to be excited about raising taxes to pay for poor people's healthcare.

Here's another possible incentive for action in January: By then, a proposed initiative to boost the cigarette tax by \$2 a pack may have qualified for the 2016 ballot. If so, that might motivate the influential tobacco lobby to compromise on a reduced tax that could help finance Medi-Cal. At least it's theoretically possible.

There are bills to tax and regulate tobacco and electronic cigarettes pending in the special session. That's one reason Democrats are reluctant to adjourn until at least late January.

"We claim to be the leader in the country on tobacco control," says Sen. Richard Pan (D-Sacramento), author of a cigarette tax bill. "But we have the lowest tobacco tax of any state surrounding us." It's 87 cents per pack.

If the Legislature were to adjourn the special session on Jan. 31, say, the right-to-die bill still wouldn't take effect until May 1.

If it waited until the end of the regular session on Aug. 31, the measure wouldn't be implemented until Nov. 29. And if the Legislature never formally pulled the plug and just went out of business after the November election, the terminally ill would have to wait until March 1, 2017, to begin the process of assisted death.

How many dying patients will suffer pain needlessly while being denied the option promised by Sacramento politicians to end their lives with a physician-prescribed pill?

"Every week counts, every day counts," Wolk says.

The Legislature should get it gear — or get out of the way.

george.skelton@latimes.com

**8a. STATE PLAN
GOALS/LEGISLATIVE
PRIORITIES 2016**

DETAIL SHEET
AGENDA ITEM
Employment First Committee
Data Request

ISSUE: Employment data

SUMMARY: Request to DDS and Employment Development Department (EDD) to expand their MOU for data sharing.

COUNCIL STRATEGIC PLAN GOALS: Goal #8: The State of California will adopt an Employment First policy which reflects inclusive and gainful employment as the preferred outcome for working age individuals with developmental disabilities. Goal #9: Working age adults with developmental disabilities have the necessary information, tools, and supports to succeed in inclusive, gainful work.

BACKGROUND: Based on EDD and DDS data, only 14% of working age adults with developmental disabilities receives wages, compared with 24% nationally. Their average earnings are less than \$500 per month. Based on the National Core Indicators Adult Consumer Survey in California, only 8% work in integrated or competitive employment.

PRIOR COUNCIL ACTIVITY: The Council sponsored legislation to establish the Employment First Committee (EFC). The EFC has been meeting for three years. The Council is sponsoring AB 1041 (Chesbro) to establish an employment first policy in statute. The Council is a partner agency in the California Employment Consortium for Youth (CECY), a project of national significance funded by the AIDD. Statute requires the EFC, and therefore the Council, to make recommendations on the use and development of data to track the state's progress in promoting integrated competitive employment.

ANALYSIS/DISCUSSION: It is critical for the state to track its progress on employment outcomes, and be able to do analysis of data to understand which strategies work and do not work; and who is being adequately served and who is not. The EFC and other groups have been trying to address this issue for some time. The Council, through its participation in CECY, has focused its work on data through the CECY data workgroup (affectionately called the "Data Nerds"). The workgroup has identified existing sources of data that are adequate to create a "data dashboard" for the state to track its progress. However, some additional coordination between agencies is required.

Under a current MOU between DDS and EDD, DDS pulls SSN's of all working age regional center clients. These are provided to EDD who then pulls income information associated with the SSN's and returns the data to DDS in aggregated form. This MOU took a couple years to establish, and has resulted in very valuable, high quality data describing the numbers of people making wages and their average earnings (cited above under "Background").

The CECY data workgroup and the EFC believe that the MOU could be expanded slightly to allow for a deeper analysis, without impacting consumer confidentiality issues, and with a relatively small investment of staff time. This would result in a better understanding of the distribution of earnings; It would also provide data on employment outcomes associated with various service types, age groups, and ethnic backgrounds.

EFC RECOMMENDATION: The EFC recommends that the Council request the Department of Developmental Services and the Employment Development Department expand their current data sharing MOU to include: (1) The distribution of annual average earnings, such as in 20 percentile ranges; (2) Average hourly wages and their distribution, such as in 20 percentile ranges; (3) DDS providing SSNs for subgroups to receive the analysis for the percentage of people receiving wages and their earnings, as discussed above. Gaining this data for subgroups would help us better understand the employment outcomes associated with various service types, age groups, and ethnic backgrounds.

ATTACHMENT: CECY Data Nerds Current Thinking, its report to the Council's Employment First Committee.

PREPARED: Mark Polit, May 1, 2013

Project Summary - In response to the State Council on Developmental Disabilities' goal #9 in its five year plan, Goodwill of Orange County (Goodwill) proposes to establish a community-based service model to help working age adults with developmental disabilities transition from work activity programs to community-based integrated work programs.

It was moved/seconded (Forderer/Donabed) and carried to adopt the State Plan Committee's recommendation to not fund Goodwill Industries of Orange County.

Area Board 13

Get Safe - Amount requested \$19,522

Project Summary - For the past 15 years, Get Safe has successfully worked with Regional Centers and Area Boards throughout California to create collaborative partnerships between communities and the agencies that provide services for persons with developmental disabilities through its safety education, self-advocacy forums, and diversity- awareness trainings.

It was moved/seconded (Blakemore/Weller) and carried to adopt the State Plan Committee's recommendation to fund Get Safe at the amount requested and to obtain additional information on measureable outcomes.

- g. Employment First Committee (EFC) – Kecia Weller provided a written summary of the June 17, 2014, EFC meeting. The EFC requested that the Council take action on the following four (4) items:

SCDD Legislation on Employment Data

It was moved/seconded (Weller/Ning) and carried to sponsor legislation that will require the Employment Development Department and/or the Franchise Tax Board to release income data on individuals who are regional center clients to the Department of Developmental Services (DDS). The legislation would also require that DDS collect data from regional center service providers on all working age regional center clients on hours worked, income earned, type of job, and other relevant employment data to better assess the

implementation of the employment first policy. The legislation will contain provisions to protect individual privacy. (5 abstentions)

Sheltered Workshops and Subminimum Wage Resolution

It was moved/seconded (Weller/Lewis) and carried to adopt EFC's policy on the phasing out of sheltered work and subminimum wage and the transition to integrated competitive employment. (5 abstentions)

Assembly Joint Resolution (AJR) 36

It was moved/seconded (Smith/Weller) and carried to support AJR 36 which if passed, would request that the United States Congress phase out the use of subminimum wage. (5 abstentions)

Day Services Holidays

It was moved/seconded (Forderer/Weller) and carried that the Council write a letter to DDS requesting the review of the uniform holiday schedule as it impacts people with developmental disabilities. (5 abstentions)

7. STATEWIDE SELF-ADVOCACY NETWORK (SSAN)

David Forderer provided a written summary which highlighted the accomplishments of the June 23 and 24, 2014 SSAN meeting.

8. STAFF REPORTS

The Interim Executive Director, Chief Deputy Director, Deputy Director of Policy and Planning, and Area Board Executive Directors provided written reports that were included in the packet.

9. CLOSED SESSION – PERSONNEL

The Council went into closed session.

10. RECONVENE OPEN SESSION

Chapter 387

(Senate Bill 853)

AN ACT concerning

Ethan Saylor ~~Center~~ Alliance for Self-Advocates as Educators

FOR the purpose of establishing the Ethan Saylor ~~Center~~ Alliance for Self-Advocates as Educators ~~as an independent unit of State government in the Department of Disabilities~~; establishing the purpose of the ~~Center~~ Alliance; ~~providing for the location and staffing of the Center; requiring the Center to develop and update a certain plan to establish community inclusion training priorities and goals; specifying other functions and duties of the Center~~ establishing certain requirements for the Alliance; establishing the ~~Governing Board of the Center~~ a Steering Committee for the Alliance; providing for the composition, ~~chair, and staffing~~ of the ~~Governing Board~~ Steering Committee; providing for the ~~appointment and~~ terms of certain members of the ~~Governing Board~~ Steering Committee; prohibiting a member of the ~~Governing Board~~ Steering Committee from receiving certain compensation, but authorizing the reimbursement of certain expenses; providing for the duties of the ~~Governing Board~~ Steering Committee; providing for the funding of the ~~Center~~ Alliance; ~~requiring the Governing Board to make a certain report to the Governor and the General Assembly on or before a certain date each year~~; defining certain terms; and generally relating to the establishment of the Ethan Saylor ~~Center~~ Alliance for Self-Advocates as Educators.

BY repealing and reenacting, without amendments,
 Article – Health – General
 Section ~~7-101(h)~~ 7-101(f) and (k)
 Annotated Code of Maryland
 (2009 Replacement Volume and 2014 Supplement)

~~BY repealing and reenacting, without amendments,
 Article – Human Services
 Section 7-202
 Annotated Code of Maryland
 (2007 Volume and 2014 Supplement)~~

BY adding to
 Article – Human Services
 Section 7-501 through ~~7-505~~ 7-504 to be under the new subtitle “Subtitle 5. Ethan Saylor ~~Center~~ Alliance for Self-Advocates as Educators”
 Annotated Code of Maryland
 (2007 Volume and 2014 Supplement)

Preamble

WHEREAS, Over 90,000 Marylanders are individuals with intellectual and developmental disabilities, such as autism, cerebral palsy, and Down syndrome; and

WHEREAS, Individuals with intellectual and developmental disabilities, like all other Marylanders, have the right to full, meaningful, and equal participation in all aspects of community life; and

WHEREAS, Although individuals with intellectual and developmental disabilities may have cognitive challenges, these individuals, when supported and encouraged, are able to use their skills, capabilities, and experiences to make meaningful contributions to their families and communities; and

WHEREAS, The skills, capabilities, and experiences of individuals with intellectual and developmental disabilities are often unrecognized, underestimated, or misunderstood; and

WHEREAS, Many governmental and nongovernmental entities, including law enforcement officials and other first responders, receive limited training about interacting, supporting, and working with individuals with intellectual and developmental disabilities; and

WHEREAS, The lack of knowledge and understanding has a widespread and significant negative impact on the inclusion of individuals with intellectual and developmental disabilities in community life; and

WHEREAS, True inclusion of individuals with intellectual and developmental disabilities, so that the individuals feel welcomed and accepted in their communities, starts with self-advocates having the central role in educating persons that interact with individuals with intellectual and developmental disabilities; and

WHEREAS, On January 12, 2013, Robert Ethan Saylor, a 26-year-old Marylander with an intellectual disability, died in a movie theater in his community in Frederick County; and

WHEREAS, The Governor subsequently created the Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities; and

WHEREAS, The December 2013 report of the Commission for Effective Community Inclusion of Individuals with Intellectual and Developmental Disabilities recommended the establishment of a new center to prepare, coordinate, and support self-advocates as active educators in training programs on community inclusion and effective communication with individuals with intellectual and developmental disabilities for persons in various sectors across the State, including education, transportation, and health care; now, therefore,

SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

Article – Health – General

7-101.

(f) “Developmental disability” means a severe chronic disability of an individual that:

(1) Is attributable to a physical or mental impairment, other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments;

(2) Is manifested before the individual attains the age of 22;

(3) Is likely to continue indefinitely;

(4) Results in an inability to live independently without external support or continuing and regular assistance; and

(5) Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are individually planned and coordinated for the individual.

(k) “Intellectual disability” means a developmental disability that is evidenced by significantly subaverage intellectual functioning and impairment in the adaptive behavior of an individual.

Article – Human Services

~~7-202.~~

~~(a) An individual has a functional disability if the individual has a severe, chronic disability that:~~

~~(1) is attributable to a mental or physical impairment or a combination of mental and physical impairments, including a head injury;~~

~~(2) is likely to continue indefinitely;~~

~~(3) results in substantial functional limitations in at least three of the following areas of major life activity:~~

~~(i) self care;~~

~~(ii) receptive and expressive language;~~

~~(iii) learning;~~

- ~~(iv) mobility;~~
- ~~(v) self-direction;~~
- ~~(vi) capacity for independent living; and~~
- ~~(vii) economic self-sufficiency; and~~
- ~~(4) reflects the individual's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services that are:~~
 - ~~(i) lifelong or of extended duration; and~~
 - ~~(ii) individually planned and coordinated.~~

~~(b) An individual has a developmental disability if the individual has a functional disability that is manifested before the individual attains the age of 22 years.~~

SUBTITLE 5. ETHAN SAYLOR ~~CENTER~~ ALLIANCE FOR SELF-ADVOCATES AS EDUCATORS.

7-501.

(A) IN THIS SUBTITLE THE FOLLOWING WORDS HAVE THE MEANINGS INDICATED.

~~**(B) "CENTER" MEANS THE ETHAN SAYLOR CENTER FOR SELF-ADVOCATES AS EDUCATORS.**~~

(B) "ALLIANCE" MEANS THE ETHAN SAYLOR ALLIANCE FOR SELF-ADVOCATES AS EDUCATORS.

(C) "COMMUNITY INCLUSION" MEANS CIRCUMSTANCES IN WHICH INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES ARE WELCOMED, SUPPORTED, AND INCLUDED IN ALL ASPECTS OF SOCIETY.

(D) "DEVELOPMENTAL DISABILITY" HAS THE MEANING STATED IN § 7-101 OF THE HEALTH - GENERAL ARTICLE.

~~**(D) "GOVERNING BOARD" MEANS THE GOVERNING BOARD OF THE ETHAN SAYLOR CENTER FOR SELF-ADVOCATES AS EDUCATORS.**~~

(E) "INTELLECTUAL DISABILITY" HAS THE MEANING STATED IN ~~§ 7-101(K)~~ 7-101 OF THE HEALTH - GENERAL ARTICLE.

(F) "STEERING COMMITTEE" MEANS THE STEERING COMMITTEE FOR THE ETHAN SAYLOR ALLIANCE FOR SELF-ADVOCATES AS EDUCATORS.

7-502.

(A) THERE IS AN ETHAN SAYLOR ~~CENTER~~ ALLIANCE FOR SELF-ADVOCATES AS EDUCATORS IN THE DEPARTMENT.

(B) ~~THE CENTER IS AN INDEPENDENT UNIT WITHIN STATE GOVERNMENT.~~

(C) THE PURPOSE OF THE ~~CENTER~~ 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 PERSONS ABOUT APPROPRIATE AND EFFECTIVE INTERACTIONS WITH INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES.

(D) ~~THE CENTER SHALL BE BASED AT A UNIVERSITY IN THE STATE AS DETERMINED BY THE GOVERNING BOARD.~~

(E) (1) ~~THE HEAD OF THE CENTER SHALL BE AN EXECUTIVE DIRECTOR OR CO DIRECTORS, AS DETERMINED AND APPOINTED BY THE GOVERNING BOARD.~~

(2) ~~THE EXECUTIVE DIRECTOR OR AT LEAST ONE OF THE CO DIRECTORS SHALL BE AN INDIVIDUAL WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY.~~

(F) ~~THE CENTER MAY EMPLOY THE ADDITIONAL STAFF NECESSARY TO CARRY OUT THE CENTER'S FUNCTIONS AS PROVIDED IN THE STATE BUDGET.~~

(G) (1) ~~THE CENTER, IN CONSULTATION WITH THE GOVERNING BOARD AND STAKEHOLDERS, SHALL DEVELOP A 3 YEAR PLAN TO ESTABLISH COMMUNITY INCLUSION TRAINING PRIORITIES AND GOALS.~~

(2) ~~THE INITIAL PLAN SHALL:~~

(H) ~~BE BASED ON A COMPREHENSIVE NEEDS ASSESSMENT, INCLUDING AN ASSESSMENT OF EXISTING TRAINING RESOURCES AND A GAP ANALYSIS;~~

~~(H) CONTINUE AND EXPAND ON THE WORK OF THE COMMISSION FOR EFFECTIVE COMMUNITY INCLUSION OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES BY PRIORITIZING THE TRAINING NEEDS OF LAW ENFORCEMENT OFFICERS AND OTHER FIRST RESPONDERS; AND~~

~~(HH) BE APPROVED BY THE GOVERNING BOARD.~~

~~(3) (H) THE CENTER ANNUALLY SHALL UPDATE THE 3-YEAR PLAN.~~

~~(H) THE UPDATED PLANS MAY FOCUS ON THE TRAINING NEEDS OF ADDITIONAL PUBLIC AND PRIVATE SECTORS SUCH AS COURTS, HEALTH CARE PROVIDERS, SCHOOLS, OR BUSINESSES.~~

~~(H) THE CENTER SHALL PERFORM THE FOLLOWING FUNCTIONS AND DUTIES TO ACHIEVE THE GOALS ESTABLISHED IN THE 3-YEAR PLAN:~~

~~(1) COLLABORATE WITH THE DEPARTMENT OF DISABILITIES, DISABILITY ORGANIZATIONS, COMMUNITY ORGANIZATIONS, SELF ADVOCATES, FAMILIES, AND OTHER STAKEHOLDERS TO IMPLEMENT A COMPREHENSIVE, COORDINATED APPROACH TO IDENTIFYING, PREPARING, AND SUPPORTING INDIVIDUALS TO BE SELF-ADVOCATE EDUCATORS;~~

~~(2) IN PARTNERSHIP WITH STAKEHOLDERS:~~

~~(H) IDENTIFY BEST PRACTICES FOR TRAINING TO MEET THE PRIORITIES ESTABLISHED IN THE 3-YEAR PLAN;~~

~~(H) IF TRAINING RESOURCES TO ADDRESS THE PRIORITIES ESTABLISHED IN THE 3-YEAR PLAN ALREADY EXIST, CONNECT PERSONS IN THE PRIORITY SECTORS WITH SELF-ADVOCATE EDUCATORS, OR ENTITIES THAT INCLUDE SELF-ADVOCATE EDUCATORS IN A CENTRAL ROLE, TO PROVIDE THE TRAINING;~~

~~(HH) IF TRAINING RESOURCES TO ADDRESS THE PRIORITIES ESTABLISHED IN THE 3-YEAR PLAN DO NOT EXIST:~~

~~1. DEVELOP TRAINING RESOURCES; OR~~

~~2. CONTRACT WITH A PERSON FOR THE DEVELOPMENT OF TRAINING RESOURCES;~~

~~(IV) PROMOTE INTERAGENCY EFFORTS THAT SUPPORT COMMUNITY INCLUSION, INCLUDING IDENTIFYING OPPORTUNITIES FOR~~

~~SELF-ADVOCATE EDUCATORS TO PARTICIPATE IN TRAINING PROGRAMS THROUGHOUT STATE GOVERNMENT; AND~~

~~(v) PROVIDE TRAINING WITH SELF-ADVOCATE EDUCATORS IN CENTRAL AND LEADING ROLES;~~

~~(3) IF A PERSON RECEIVING TRAINING DOES NOT PROVIDE NECESSARY SUPPORT SERVICES FOR SELF-ADVOCATE EDUCATORS, PROVIDE OR IDENTIFY SOURCES TO PROVIDE THE SUPPORT SERVICES, INCLUDING COMPENSATION FOR TRAINING ACTIVITIES, TRANSPORTATION, AND OTHER RELATED EXPENSES;~~

~~(4) ESTABLISH A CLEARINGHOUSE TO DISSEMINATE INFORMATION ON BEST PRACTICES, STRATEGIES, AND RESOURCES FOR:~~

~~(i) SELF-ADVOCATES AS EDUCATORS; AND~~

~~(ii) THE COMMUNITY INCLUSION TRAINING PRIORITIES ESTABLISHED IN THE 3-YEAR PLAN;~~

~~(5) INITIATE COLLABORATIONS AND FACILITATE COORDINATION AMONG APPROPRIATE GOVERNMENTAL UNITS AND OTHER PERSONS TO LEVERAGE EXISTING RESOURCES FOR TRAINING DELIVERY; AND~~

~~(6) FOSTER COORDINATION AMONG PERSONS THAT HAVE TRAINING NEEDS AND PERSONS THAT PROVIDE TRAINING TO MEET THE PRIORITIES ESTABLISHED IN THE 3-YEAR PLAN.~~

(C) THE ALLIANCE SHALL:

(1) BE GUIDED BY THE STEERING COMMITTEE;

(2) BUILD ON THE WORK OF THE COMMISSION FOR EFFECTIVE COMMUNITY INCLUSION OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES BY PRIORITIZING THE TRAINING NEEDS OF LAW ENFORCEMENT OFFICERS;

(3) CONNECT LAW ENFORCEMENT TRAINERS WITH:

(i) SELF-ADVOCATE EDUCATORS; OR

(ii) ENTITIES THAT USE SELF-ADVOCATE EDUCATORS IN A CENTRAL ROLE WHEN PROVIDING TRAINING;

(4) IDENTIFY AND SUPPORT THE DEVELOPMENT OF SELF-ADVOCATE EDUCATORS;

(5) IDENTIFY RESOURCES NEEDED TO PREPARE AND SUPPORT SELF-ADVOCATE EDUCATORS; AND

(6) PROMOTE COLLABORATIVE EFFORTS THAT SUPPORT COMMUNITY INCLUSION.

7-503.

(A) ~~THERE IS A GOVERNING BOARD OF~~ STEERING COMMITTEE FOR THE CENTER ALLIANCE.

(B) ~~THE GOVERNING BOARD~~ STEERING COMMITTEE SHALL INCLUDE THE FOLLOWING MEMBERS:

(1) ~~THE SECRETARY OF DISABILITIES,~~ OR THE SECRETARY'S DESIGNEE;

(2) ~~THE STATE SUPERINTENDENT OF SCHOOLS, OR THE STATE SUPERINTENDENT'S DESIGNEE;~~

(3) ~~THE SECRETARY OF STATE POLICE, OR THE SECRETARY'S DESIGNEE~~ THE SUPERINTENDENT OF THE STATE POLICE, OR THE SUPERINTENDENT'S DESIGNEE;

~~(4)~~ (3) THE EXECUTIVE DIRECTOR OF THE POLICE AND CORRECTIONAL TRAINING COMMISSIONS, OR THE EXECUTIVE DIRECTOR'S DESIGNEE;

~~(5) THE EXECUTIVE DIRECTOR OF THE JUDICIAL TRAINING INSTITUTE, OR THE EXECUTIVE DIRECTOR'S DESIGNEE;~~

~~(6) THE PUBLIC DEFENDER OF MARYLAND OR THE PUBLIC DEFENDER'S DESIGNEE;~~

~~(7) THE EXECUTIVE DIRECTOR OF THE MARYLAND INSTITUTE FOR EMERGENCY MEDICAL SERVICE SYSTEMS, OR THE EXECUTIVE DIRECTOR'S DESIGNEE;~~

~~(8)~~ (4) THE DEPUTY SECRETARY FOR DEVELOPMENTAL DISABILITIES IN THE DEPARTMENT OF HEALTH AND MENTAL HYGIENE, OR THE DEPUTY SECRETARY'S DESIGNEE; AND

(5) THE FOLLOWING INDIVIDUALS, APPOINTED BY THE SECRETARY:

~~(9)~~ (I) A REPRESENTATIVE OF PEOPLE ON THE GO MARYLAND;

~~(10)~~ (II) A REPRESENTATIVE OF THE MARYLAND DEVELOPMENTAL DISABILITIES COUNCIL;

~~(11)~~ (III) ~~A REPRESENTATIVE OF A COMMUNITY-BASED ORGANIZATION THAT SUPPORTS~~ TWO REPRESENTATIVES OF COMMUNITY-BASED ORGANIZATIONS THAT SUPPORT PEOPLE WITH INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES; AND

~~(12)~~ (IV) ~~SIX~~ FOUR MEMBERS OF THE PUBLIC WITH KNOWLEDGE OF INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES, INCLUDING AT LEAST TWO SELF-ADVOCATES AND A FAMILY MEMBER OF AN INDIVIDUAL WITH AN INTELLECTUAL DISABILITY OR DEVELOPMENTAL DISABILITY, ~~EACH APPOINTED BY THE GOVERNOR WITH THE ADVICE AND CONSENT OF THE SENATE;~~

(V) A REPRESENTATIVE OF THE MARYLAND ASSOCIATION OF BOARDS OF EDUCATION; AND

(VI) OTHER MEMBERS DEEMED NECESSARY TO CARRY OUT THE WORK OF THE STEERING COMMITTEE.

~~(C) THE GOVERNOR MAY APPOINT ADDITIONAL MEMBERS BASED ON THE PRIORITIES ESTABLISHED IN THE 3-YEAR PLAN.~~

~~(D) THE GOVERNING BOARD SHALL ELECT A CHAIR FROM AMONG ITS MEMBERS.~~

~~(E)~~ (C) A MEMBER APPOINTED BY THE ~~GOVERNOR~~ SECRETARY:

(1) ~~SERVES AT THE PLEASURE OF THE GOVERNOR;~~

~~(2)~~ SERVES FOR A TERM OF 3 YEARS AND UNTIL A SUCCESSOR IS APPOINTED AND QUALIFIES; AND

~~(3)~~ (2) MAY BE REAPPOINTED ~~BUT MAY NOT SERVE MORE THAN TWO CONSECUTIVE TERMS.~~

~~(F) (1) UNTIL THE CENTER IS ESTABLISHED, THE DEPARTMENT OF DISABILITIES SHALL PROVIDE STAFF FOR THE GOVERNING BOARD;~~

~~(2) AFTER THE CENTER IS ESTABLISHED, THE CENTER SHALL PROVIDE STAFF FOR THE GOVERNING BOARD;~~

~~(G) (D) A MEMBER OF THE GOVERNING BOARD STEERING COMMITTEE:~~

~~(1) MAY NOT RECEIVE COMPENSATION AS A MEMBER OF THE GOVERNING BOARD STEERING COMMITTEE; BUT~~

~~(2) IS ENTITLED TO REIMBURSEMENT FOR EXPENSES UNDER THE STANDARD STATE TRAVEL REGULATIONS, AS PROVIDED IN THE STATE BUDGET.~~

~~(H) (E) THE GOVERNING BOARD STEERING COMMITTEE SHALL:~~

~~(1) DEVELOP AN IMPLEMENTATION PLAN TO PHASE IN THE ESTABLISHMENT AND OPERATION OF THE CENTER;~~

~~(2) SELECT A UNIVERSITY TO OPERATE THE CENTER;~~

~~(I) THROUGH A COMPETITIVE PROCESS; AND~~

~~(II) GIVING CONSIDERATION TO THE EXPERIENCE, KNOWLEDGE, AND CAPACITY OF THE UNIVERSITY;~~

~~(3) PROVIDE GENERAL OVERSIGHT AND DIRECTION TO THE CENTER;~~

~~(4) APPROVE THE ANNUAL BUDGET FOR THE CENTER; AND~~

~~(5) MONITOR AND EVALUATE THE CENTER'S ACTIVITIES AND OUTCOMES.~~

(1) DEVELOP PARAMETERS FOR THE ALLIANCE, INCLUDING EXPECTED OUTCOMES FOR AND EVALUATION OF THE ALLIANCE;

(2) SELECT ENTITIES TO OPERATE THE ALLIANCE THROUGH A COMPETITIVE PROCESS;

(3) PROVIDE GENERAL OVERSIGHT OF THE ALLIANCE;

(4) APPROVE THE BUDGET FOR THE ALLIANCE;

(5) REVIEW THE ALLIANCE'S ACTIVITIES AND OUTCOMES; AND

(6) DEVELOP RECOMMENDATIONS FOR SUSTAINABILITY AND EXPANSION OF THE ALLIANCE, INCLUDING:

(I) COSTS OF SUSTAINING AND EXPANDING THE ALLIANCE;

(II) POTENTIAL SOURCES OF FUNDING FOR THE ALLIANCE; AND

(III) COMPENSATION AND SUPPORTS FOR SELF-ADVOCATE EDUCATORS.

7-504.

(A) SUBJECT TO SUBSECTION (B) OF THIS SECTION, THE OPERATION OF THE ~~CENTER~~ ALLIANCE SHALL BE SUPPORTED BY:

(1) APPROPRIATIONS PROVIDED IN THE ANNUAL STATE BUDGET;

(2) GRANTS OR OTHER ASSISTANCE FROM FEDERAL, STATE, OR LOCAL GOVERNMENT; AND

(3) ANY OTHER MONEY MADE AVAILABLE TO THE ~~CENTER~~ ALLIANCE FROM ANY PUBLIC OR PRIVATE SOURCE.

~~(B) THE GOVERNING BOARD MAY NOT USE MORE THAN 10% OF THE CENTER'S FUNDING FOR INDIRECT COSTS~~ THE OPERATION OF THE ALLIANCE IS SUBJECT TO THE LIMITATIONS OF THE STATE BUDGET.

~~7-505.~~

~~(A) THE GOVERNING BOARD SHALL REPORT TO THE GOVERNOR AND, IN ACCORDANCE WITH § 2-1246 OF THE STATE GOVERNMENT ARTICLE, THE GENERAL ASSEMBLY ON OR BEFORE DECEMBER 15 OF EACH YEAR.~~

~~(B) THE REPORT SHALL INCLUDE:~~

~~(1) A LIST OF THE MAJOR ACTIVITIES OF THE CENTER, INCLUDING THE TRAINING ACTIVITIES CARRIED OUT BY SELF-ADVOCATE EDUCATORS;~~

~~(2) A SUMMARY OF THE CENTER'S PROGRESS ON THE GOALS AND OBJECTIVES ESTABLISHED IN THE 3 YEAR PLAN, INCLUDING EVALUATION AND OUTCOME DATA;~~

~~(3) A SUMMARY OF BARRIERS ENCOUNTERED AND LESSONS LEARNED; AND~~

~~(4) AN UPDATE ON THE CURRENT STATUS AND EFFECTIVENESS OF THE CENTER.~~

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect July 1, 2015.

Approved by the Governor, May 12, 2015.