COUNCIL MEETING NOTICE/AGENDA
POSTED AT: www.scdd.ca.gov

DATE: January 28, 2020
TIME: 10:00 AM until 4:00 PM

MEETING LOCATION:
Hilton – Sacramento Arden-West
2200 Harvard Street
Sacramento, CA 95815

COUNCIL CHAIR: Maria Marquez

Item 1. CALL TO ORDER

Item 2. ESTABLISH QUORUM

Item 3. WELCOME AND INTRODUCTIONS

Item 4. 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 read aloud.

Item 5. APPROVAL OF NOVEMBER 2019 MINUTES
Item 6. CHAIR REPORT AND COMMITTEE REPORTS

- Chair Report, S.S.D.A.C. and P.S.P.S. Updates
- Statewide Self-Advocacy Network Report
- Self-Advocates Advisory Committee Report

Item 7. EXECUTIVE DIRECTOR REPORT AND STAFF REPORTS

- Deputy Director of Administration Report
- Deputy Director of Policy Report
- C.R.A./V.A.S. Update Report
- Developmental Center Closure Update
- QA Project Update Report

Item 8. 2020-2021 GOVERNOR’S PROPOSED BUDGET

Presented by Marko Mijic, CHHS Deputy Secretary and Brian Winfield, DDS Chief Deputy Director

Item 9. SCDD 2020 GOALS AND POLICY PRIORITIES

Item 10. HOUSING UPDATE

Presented by Micaela Connery, CEO of The Kelsey, and Aaron Carruthers, SCDD Executive Director

Item 11. MASTER PLAN ON AGING

Presented by Joseph Rodrigues, State Long-Term Care Ombudsman, Department of Aging

Item 12. REPORT ON 2020 CENSUS COUNT

Presented by Vanessa Cuellar, Statewide Youth Organizer and Kyla Aquino Irving, Communications & Marketing Director, California Foundation for Independent Living Centers (CFILC)

Item 13. ASSEMBLY SELECT COMMITTEE ON I.D.D. HEARING

Presented by Wesley Witherspoon (S.A.) and Cindy Smith, Deputy Director of Policy and Public Affairs

Item 14. NEXT MEETING DATE & ADJOURNMENT

Next meeting: March 17, 2020 at Doubletree Sacramento, 2001 Point West Way, Sacramento, CA 95815
Accessibility:
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 this meeting should contact (916) 263-7919. Requests must be received by 5 business days prior to the meeting.

Materials:
Meeting documents and presentations for an agenda item must be submitted to SCDD no later than 2 business days prior to the meeting.

All times indicated and the order of business are approximate and subject to change.
JANUARY 28, 2020

AGENDA ITEM 5
ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Approval of November 2019 Minutes

The minutes from the November 2019 Council meeting have been included in the packet for review and approval.

Action Recommended
Approve the November 2019 Minutes.
DRAFT
Council Meeting Minutes
November 14, 2019

Members Present
Andrea Vergne (F.A.)
Aubyn Stahmer
Barbara Boyd
Catherine Blakemore
Cindy Chiu
David Pegos (F.A.)
Evelyn Schaeffer
Francis Lau (F.A.)
John Doyle
Joseph Rodrigues
Joyce McNair (F.A.)
Julie Austin (F.A.)
Julie Neward (F.A.)
Julio Garnica (S.A.)
Kilolo Brodie (F.A.)
Larry Yin
Lee Bycel (F.A.)
Maria Marquez (S.A.)
Matthew Lagrand (S.A.)
Nicole Adler (S.A.)
Rosie Ryan (S.A.)
Sandra Aldana (S.A.)
Wesley Witherspoon
(S.A.)

Members Absent
Diane Ambrose (F.A.)
Jeana Eriksen (S.A.)
Karen Millender (F.A.)
Kara Ponton (S.A.)
Kim Levy Rothschild
(F.A.)
Marko Mijic
Olivia Raynor

Others Attending (Continued)
Jennifer Gonzalez
Karen Mulvany
Laura Larson
Lavonne Fawver
Lea Park-Kim
Lisa Hooks
Mary Agnes Nolan
Mary Ellen Stives
Megan Owen
Michelle Heid
Midhun Tripuraneni
Nicholas Epstein
Palmira Kyle
Ramsey Tau
Ravita Devi
Riana Hardin
Rob Lewis
Ronny Zavosky
Scarlett von Thenen
Sheraden Nichols
Sidney Jackson
Sonya Bingaman
Tamic Foots-Rachal
Yolanda Cruz

1. CALL TO ORDER
Interim Chair Maria Marquez called the meeting to order at 10:15 A.M.
2. **ESTABLISH QUORUM**
   A quorum was established.

3. **WELCOME AND INTRODUCTIONS**
   Councilmembers and others in attendance introduced themselves.

4. **PUBLIC COMMENTS**
   April Wick from Resources for Independent Living spoke about the 2020 Census and her organization’s involvement on a Census Complete Count Committee. She emphasized the importance of having more census count participation from the I/DD community. Rob Lewis from GT Independence also spoke, offering his organization as an available resource for more information about the Self-Determination Program.

   At the end of public comment, Interim Chair Marquez proposed changing the order of agenda items for the day. This was so that the Council could enter an early closed session to complete the Executive Director evaluation. There were no objections to this change.

5. **APPROVAL OF SEPTEMBER 2019 MINUTES**
   **Action 1**
   It was moved/seconded (Witherspoon [S.A.]/Austin [F.A.]) and carried to approve the September 2019 Council meeting minutes. (See page 8 for the voting record of members present.)

6. **2019-2020 CHAIR AND VICE CHAIR ELECTIONS**
   W&I Code Section 4535(b) requires the Council to elect its Chairperson and Vice Chairperson by a majority vote. The terms are for November 2019 through December 2020. Nominations were made by both the Nominating Committee and by nominations from the floor. Candidates were considered as follows (in alphabetical order):

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<th>Vice Chair</th>
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<td>Matthew Lagrand (S.A.)</td>
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Legend:
SA = Self-Advocate
FA = Family Advocate
DNP = Did Not Participate/Not Present
N/A = Not Available
An election was held separately for each office. The election for Chair was held first. Following member statements by the candidates for Chair, an open vote was taken. Interim Chair Maria Marquez won the majority vote for Chairperson with 13 votes, Councilmember Andrea Vergne followed with 4 votes, followed by Councilmember Wesley Witherspoon with 3 votes, and Councilmember Matthew Lagrand with 2 votes.

Following member statements by the candidates for Vice Chair, a vote was taken. In the initial election, Interim Vice Chair Julie Austin received 11 votes, Councilmember Andrea Vergne followed with 5 votes, followed by Councilmember Sandra Aldana with 3 votes, Councilmember Matthew Lagrand with 3 votes, and Councilmember Wesley Witherspoon with 0 votes. Since there was not a clear majority, a second election was held as a runoff between the two candidates with the highest votes. In the final election, Vice Chair Julie Austin won the majority vote for Vice Chairperson with 15 votes, followed by Councilmember Andrea Vergne with 7 votes.

Chair Maria Marquez and Vice Chair Julie Austin will serve in their positions until December 2020. (Please see page 9 for the voting record of members present.)

7. CHAIR REPORT
Following the officer elections, Chair Maria Marquez expressed her gratitude to all members and recognized the members who would be leaving the Council – Catherine Blakemore and Kris Kent. They have been strong advocates working with the SCDD for many years and will be missed from the Council. Chair Marquez and Executive Director Carruthers signed certificates of achievement to be given to the outgoing members.

Marquez reported that she and Vice Chair Julie Austin worked closely together to complete the Executive Director evaluation. She has also been busy with the Self-Determination Advisory Committee, working on goals for the committee and how independent facilitators will be rolled out as part of the Self-Determination Program.

Recently, many policy letters have been sent to the Governor on behalf of SCDD with the assistance of Deputy Director Cindy Smith, and Marquez thanked Smith for all her efforts.
Thinking about the future of the Council, Chair Marquez asked that Councilmembers consider the following: how to build the Council in a different direction with different forms of advocacy; what would make the Council run smoother and what would bring us to the forefront of advocacy in the I/DD community; and how we could have a greater voice and presence in general. Marquez went on to say she has lots of ideas about potential committee restructuring versus task force creations, as well as different regional advisory committees and taking more advantage of the opportunities out there. Councilmember Andrea Vergne asked if members could submit some suggestions for consideration in the new year, which was welcomed by the Chair and Vice Chair. More feedback will be requested in January.

8. EXECUTIVE DIRECTOR REPORT AND STAFF REPORTS

Executive Director Aaron Carruthers provided a written report to update Councilmembers on the following items.

The State Plan work reached over 240,000 people in August and September. SCDD did a lot of work at the end of the year, with a total of 1.9 million people being reached throughout the federal fiscal year.

There has been a lot of work with the Statewide Self-Determination Advisory Committee (SSDAC) around their request to have more independence from the Council. The Committee also met to discuss the goals they set and what’s happening in the program. October 1, 2018 was when the first round of names was drawn for the Self-Determination Program; since then 18% of the participants have dropped out for various reasons. New names will be drawn by the Department of Developmental Services (DDS) on November 22, 2019. They will be seeking individuals who are age 42 or older, as well as siblings of people who are already enrolled, and local advisory committee members. One of the goals of the next selection is to continue to represent the racial and ethnic diversity of each catchment area.

Executive Director Carruthers attended the newly formed Interagency Advisory Committee on Apprenticeship (IACA) in early November. There is a lot of opportunity for apprenticeships for people with I/DD in the fields of civil service, health care, technology and building trades. SCDD will
continue to support advocacy for people with I/DD to have access to these kinds of opportunities.

Regarding public safety, we continue to distribute information to our community as to where they can get advice about power shut offs. We continue to communicate with the statewide utilities, noting that their practices and procedures are not uniform across the state of California. SCDD will send a letter to the utility providers, stating that we would like better response and communication from them. The major goal is to let the utilities know how the power shut offs are affecting people with disabilities.

The Council received a grant from DDS to work with Georgetown University on disparities. In October, Executive Director Carruthers was with Georgetown representatives at Valley Mountain Regional Center and North Bay Regional Center for two days each, working with their executive teams on cultural competence training. This is part of a yearlong project.

In national leadership news, the Administration on Community Living (ACL) came to the recent Executive Director Leadership Summit (a meeting of Executive Directors of all state Councils). They spoke about what the ACL’s expectations for Councils are, and Executive Director Carruthers has been asked to be part of a five-member Executive Director panel to work on building the structures for improved communication between the ACL and all fifty-six (56) DD Councils.

Under administration, the SCDD budget continues to remain strong. We can likely expect that the federal funding will continue to flow at the same rate, with no reductions or additions. Additionally, it was reported that the Council staff vacancy rate is low.

Lastly AB 434, which requires the State of California to provide and maintain website accessibility, has been signed into law. As a state agency, SCDD’s website will be in compliance with the higher accessibility standards by the end of the year.

Staff reports were made available in the packet and as handouts.
9. **STATEWIDE SELF-ADVOCACY NETWORK (SSAN) REPORT**

SSAN representative Wesley Witherspoon presented the November SSAN report to Councilmembers. He spoke about planning for the next SSAN meeting which will take place December 4th and 5th in Sacramento. The SSAN leadership team continues to use their combined skills and abilities to foster a sense of community among members. Additionally, the SSAN Memorandum of Understanding (MOU) with SCDD will be discussed more at the December meeting. Councilmember Witherspoon and Chair Marquez will soon travel to Washington, D.C. to speak at the national conference for the Association of University Centers on Disabilities (AUCD).

10. **CYCLE 43 GRANTS – REQUEST FOR PROPOSALS**

Councilmember Kilolo Brodie and Executive Director Aaron Carruthers presented the Request for Proposals (RFP) for the Cycle 43 grants. Councilmember Brodie discussed the State Plan report, noting the highlights of the recent State Plan Committee meeting including the grants process, areas of emphasis, timeline and review of the overall RFP package. The State Plan Committee recommends regional grants, as opposed to statewide grants. This would make approximately $20,000 available to each region and allow each region to select a state plan goal priority based on the needs of their catchment area. The goal priority is to be identified in February by the Regional Managers with input from the local Regional Advisory Committees (RACs). The State Plan Committee recommends revising the RFP to reflect this approach and focusing on the resources the Council made available for grant writing and training.

**Action 2**

*It was moved/seconded (Brodie [F.A.]/Pegos [F.A.]) and carried to approve the Cycle 43 grant timeline, process and request for proposal package.*

(See page 8 for the voting record of members present.)

11. **2019 PROGRAM PERFORMANCE REPORT**

Executive Director Carruthers and Councilmember Brodie presented the highlights of the 2019 Program Performance Report (PPR). The PPR reflects the staff work on the State Plan that was done over the course of the last year. The State Plan is the contract with the Administration on Community Living (ACL) for the federal dollars we receive. The PPR shows the impact that staff work had and what we did with the funds that were
given to us. Activities included work in the areas of outreach and events, technical assistance and trainings, and Council and Committee meetings. The work and activities that the Council did over the past year reached a total of 1,963,804 individuals in California.

Action 3
It was moved/seconded (Aldana [S.A.]/Witherspoon [S.A.]) and carried to approve the 2019 SCDD Program Performance Report. (See page 8 for the voting record of members present.)

12. CLOSED SESSION: EXECUTIVE DIRECTOR EVALUATION
The Council went into closed session.

13. RECONVENE OPEN SESSION
Pursuant to Government Code Section 11126.3 (f), the Council reported that during closed session, the 2019 Executive Director Evaluation was unanimously approved by the Council.

14. NEXT MEETING DATE & ADJOURNMENT
The next meeting is on January 28, 2020 at the Hilton Sacramento Arden-West in Sacramento. The meeting was adjourned at 3:40 P.M.
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AGENDA ITEM 6
INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Chair Report and Committee Reports

The Chair of the Council will provide Councilmembers with an oral report to discuss recent activities and upcoming Council goals as well as updates regarding the Statewide Self-Determination Advisory Committee (S.S.D.A.C.) and Public Safety Power Shut-offs (P.S.P.S.).

As part of her report, the Chair will discuss several letters that have been sent to various organizations on SCDD’s behalf, including the following:

- Letter to Mark Schultz, Acting Assistant Secretary, U.S. Department of Education regarding the Workforce Innovation and Opportunity Act (WIOA)
- Letter to Lisa Reimers, Education Programs Consultant, California Department of Education regarding Career Technical Education (CTE)
- Letter to Mark Ghaly, Secretary, California Health and Human Services and members of the Cabinet Workgroup on Aging, regarding the Master Plan on Aging

Copies of these letters have been provided in the packet for review.

Additionally, the following committee reports will be provided for informational purposes:

- Statewide Self-Advocacy Network report (included in packet)
- Self-Advocates Advisory Committee report (handout)
November 21, 2019

Acting Assistant Secretary Mark Schultz
U.S. Department of Education
400 Maryland Ave., SW
Washington, DC 20202-7100

Dear Acting Assistant Secretary Schultz,

The undersigned organizations write to welcome you to your new role as Acting Assistant Secretary of the Office of Special Education and Rehabilitation Services (OSERS), which oversees both the Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA) at the U.S. Department of Education. Our organizations stand ready to assist you as you carry out the mission of RSA, “to provide leadership and resources to assist state and other agencies in providing vocational rehabilitation (VR) and other services to individuals with disabilities to maximize their employment, independence and integration into the community and the competitive labor market.”

We know that your office is actively considering the future of the regulations implementing the Workforce Innovation and Opportunity Act (WIOA). Through the past three Unified Agendas, Secretary DeVos has notified the public of her intent to issue a notice of proposed rulemaking to amend the regulatory definitions in the WIOA implementing regulations, 34 CFR part 361. She reaffirmed that intent in the Fall 2019 Unified Agenda that was published yesterday. The undersigned wish to unequivocally state that our groups are united in opposition of opening WIOA’s implementing regulations and believe such action would undermine the progress states and stakeholders are making in expanding opportunities for competitive integrated employment.

As you know, WIOA was passed with overwhelming bipartisan support and represents the first major legislative reform of the public workforce system in 15 years. WIOA expresses a clear policy in support of competitive integrated employment: jobs where people with disabilities are paid the same wages, have the same opportunities for advancement, and work alongside their co-workers without disabilities. Among other provisions, WIOA defines an employment outcome as competitive integrated employment; prohibits the placement of students transitioning from school into segregated subminimum wage employment without having first had the opportunity to try competitive integrated employment; mandates pre-employment transition services to prepare students for competitive integrated employment; requires people in segregated subminimum wage settings to be offered competitive integrated employment; and requires that vocational rehabilitation services support competitive integrated
employment outcomes. As directed by Congress, the Department of Education issued regulations implementing WIOA in August 2016. The WIOA regulations are very much aligned with both Congressional intent and long-standing Department of Education policy.

Despite the clear bipartisan support for WIOA, some members of Congress and stakeholders have raised some concerns about the regulations and urged that they be opened. In an effort to find a more sensible and less disruptive solution, numerous disability groups with a range of views came together to work in good faith to craft a consensus solution. Over twenty groups endorsed the position in the March 7, 2018 letter from the Consortium of Citizens with Disabilities Employment Task Force, recommending that the Department address any confusion or misunderstanding about the regulations by providing technical assistance and making clarifying changes to its sub-regulatory guidance instead of opening up the regulations. Similarly, the National Council on Disability issued a report in October 2018 recommending that the WIOA regulations not be re-opened and instead that RSA provide technical assistance to state vocational rehabilitation agencies to address any confusion or misunderstanding about how to apply the regulations. Likewise, the Senate Health, Education, Labor and Pension (HELP) Committee also issued a report making similar recommendations: “The regulations promulgated by the U.S. Department of Education should not be changed at this time. Technical assistance should be provided by the Rehabilitative Services Administration to support state-level implementation of the law and existing regulation.”

The undersigned – which reflect a wide range of stakeholders from national organizations, state agencies, employment providers, and people with disabilities and their families – firmly believe that any confusion expressed by some in the field regarding the implementation of the current WIOA regulations can be addressed most effectively through technical assistance and, if necessary, clarifying sub-regulatory guidance, not through the opening up the regulations. We remain firm in our belief that opening the WIOA regulations will undermine the important progress that has been made in expanding opportunities for people with disabilities to work in competitive integrated employment.

As you review the WIOA regulations, we hope you will closely consider the information in these two reports and the views of the wide range of undersigned organizations that strongly oppose opening the regulations and encourage you to seek other options to address any areas of confusion or misinformation. The undersigned groups stand ready to engage in thoughtful dialogue with you and your staff about this option.

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Please contact Alison Barkoff, Policy Advisor to the Collaboration to Promote Self Determination (abarkoff@cpr-us.org or 202-854-1270), Amanda Lowe, Senior Policy Analyst at the National Disability Rights Network (amanda.lowe@ndrn.org or 202-408-9514 ext. 101), or Rita Martin at the Council of State Administrators of Vocational Rehabilitation (rmartin@csavr.org or 240-994-8439) if you have any questions or to follow up on this letter.

Respectfully,

National Organizations:

American Civil Liberties Union
American Network of Community Options and Resources
Association of People Supporting Employment First (APSE)
Association of Programs for Rural Independent Living
Association of University Centers on Disabilities
Autism National Committee
Autism Society of America
Autistic Self Advocacy Network
Bazelon Center for Mental Health Law
Center for Public Representation
Collaboration to Promote Self-Determination
Community Options, Inc.
Council of Administrators of Special Education
Council of Parent Attorneys and Advocates
Council of State Administrators of Vocational Rehabilitation
Disability Resource Center
Disability Rights Education & Defense Fund
HIGH IMPACT Mission-based Consulting & Training
Mental Health America
National Association for Rights Protection and Advocacy (NARPA)
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Association of State Directors of Special Education
National Association of State Mental Health Program Directors
National Center for Learning Disabilities
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Council on Independent Living
National Disability Rights Network
National Down Syndrome Congress
National Federation of the Blind
National Independent Living Council
National Organization of Nurses with Disabilities
Paralyzed Veterans of America
State and Local Organizations:

Alabama:
Alabama Disabilities Advocacy Program

Alaska:
Southeast Alaska Independent Living, Inc. (SAIL)

Arizona:
Arizona ADAPT
Arizona APSE
Arizona Center for Disability Law
Arizona Developmental Disabilities Planning Council
DIRECT Center for Independence

Arkansas:
Disability Rights Arkansas, Inc.

California:
Access to Independence of San Diego, Inc.
California APSE
California Disability-Senior Community Action Network (CDCAN)
California Down Syndrome Advocacy Coalition
California Person Centered Advocacy Partnership
California Supported Living Network
Cal-TASH
Disability Rights California
Down Syndrome Connection of the Bay Area
Path Forward Collaborative
Service Center for Independent Life
State Council on Developmental Disabilities

Colorado:
Atlantis Community, Inc.
Colorado Assn. of People Supporting Employment First (COAPSE)
Colorado Cross-Disability Coalition
Colorado Developmental Disabilities Council
Disability Law Colorado
The Independence Center

Connecticut:
Connecticut APSE
Disability Rights Connecticut
Down Syndrome Association of Connecticut

Delaware:
Disabilities Law Program, CLASI
Down Syndrome Association of Delaware

Florida:
APSE Florida
Disability Rights Florida
University of South Florida Rehabilitation and Mental Health Counseling Program

Georgia:
Georgia Advocacy Office
Georgia APSE
Georgia Council on Developmental Disabilities

Hawaii:
Access to Independence Hawaii Branch

Idaho:
Community Partnerships of Idaho, Inc.
Disability Action Center - NW, Inc.
Idaho Council on Developmental Disabilities
Idaho State Independent Living Council
NAMI Far North, Idaho
NAMI Idaho
United Vision for Idaho

Illinois:
Access Living
Disability Resource Center
Equip for Equality
Illinois Council on Developmental Disabilities
Keshet
Statewide Independent Living Council of Illinois

Indiana:
Down Syndrome Indiana, Inc.
Indiana APSE
Indiana Disability Rights

**Iowa:**
Disability Rights Iowa
Iowa APSE
New Hope

**Kansas:**
Disability Rights Center of Kansas
Prairie Independent Living Resource Center, Inc.
Southeast KS Independent Living (SKIL) Resource Center
Statewide Independent Living Council of Kansas

**Kentucky:**
Kentucky APSE

**Louisiana:**
Louisiana Association for Persons Supporting Employment First

**Maine:**
KFI
Maine APSE
Syntro Inc.

**Maryland:**
Maryland APSE
Maryland Developmental Disabilities Council
The Parents' Place of Maryland

**Massachusetts:**
Disability Law Center
Independence Associates, Inc.
Massachusetts APSE

**Michigan:**
Michigan Protection & Advocacy Service, Inc.

**Minnesota:**
Minnesota Disability Law Center, Mid Minnesota Legal Aid
Southeastern MN Center for Independent Living, Inc.
The Arc Minnesota

**Mississippi:**
Association of People Supporting Employment First
Disability Rights Mississippi

Missouri:
Delta Center for Independent Living
Heartland Independent Living Center
Missouri APSE
Missouri Developmental Disabilities Council
Missouri Statewide Independent Living Council, Inc.
Paraquad

Montana:
Living Independently for Today & Tomorrow
North Central Independent Living Services, Inc.

Nebraska:
Disability Rights Nebraska
Down Syndrome Alliance of the Midlands
Independence Rising

Nevada:
Nevada Disability Advocacy and Law Center
Nevada Governor's Council on Developmental Disabilities, NV
People First of Nevada
Southern Nevada Center for Independent Living

New Hampshire:
Disability Rights New Hampshire
TASH New England

New Jersey:
Association for Special Children & Family
DAWN Center for Independent Living
Disability Rights New Jersey
Family Voices NJ
KIIDS
MOCEANS Center for Independent Living
New Jersey APSE
New Jersey Council on Developmental Disabilities
SPAN Parent Advocacy Network

New Mexico:
Disability Rights New Mexico
Native American Disability Law Center

New York:
Access To Independence of Cortland County, Inc.
New York State Independent Living Council, Inc. (NYSILC)
NRCIL
New York APSE

**North Carolina:**
North Carolina APSE
Disability Rights North Carolina

**North Dakota:**
Designer Genes of North Dakota, Inc.
North Dakota State Council on Developmental Disabilities
Protection & Advocacy Project

**Ohio:**
Capabilities, Ohio
CG-HHC
Greene, Inc.
Ohio APSE
Ohio TASH
The Ability Center of Greater Toledo
United Rehabilitation Services

**Oklahoma:**
Dynamic Independence

**Oregon:**
Disability Rights Oregon
Oregon APSE

**Pennsylvania:**
PA APSE
Transition Consults

**South Carolina:**
AccessAbility
Family Connection of South Carolina
Protection and Advocacy
SCAPSE

**South Dakota**
Disability Rights South Dakota

**Tennessee:**
Disability Rights Tennessee
Down Syndrome Association of Middle Tennessee
Empower Tennessee
Tennessee Council on Developmental Disabilities

**Texas:**
- Autism Society of Texas
- Disability Rights Texas
- Down Syndrome Partnership of North Texas

**Utah:**
- Disability Law Center

**Vermont:**
- Vermont APSE
- Vermont Developmental Disabilities Council

**Virginia:**
- Appalachian Independence Center, Inc.
- Blue Ridge Independent Living Center
- Center for Family Involvement
- disAbility Law Center of Virginia
- Down Syndrome Association of Northern Virginia
- The Disability Resource Center of the Rappahannock Area, Inc.

**Washington:**
- Community Employment Alliance
- Disability Rights Washington
- Total Living Concept
- Washington APSE

**West Virginia:**
- West Virginia Developmental Disabilities Council

**Wisconsin:**
- Disability Rights Wisconsin
- IndependenceFirst
- The Arc Wisconsin
- Wisconsin Association of People Supporting Employment First (WI APSE)
- Wisconsin Board for People with Developmental Disabilities
- Wisconsin Coalition of Independent Living Centers, Inc.

**Wyoming**
- Wyoming Independent Living, Inc.
- Protection & Advocacy System Inc.
- Wyoming APSE

**U.S. Virgin Islands:**
- Disability Rights Center of the Virgin Islands
Cc: Secretary Betsy DeVos, U.S. Department of Education
Dear Ms. Reimers:

The State Council on Developmental Disabilities (SCDD) was created close to 50 years ago by Congress in the Developmental Disabilities Assistance and Bill of Rights Act. The purpose of the Council in every state and territory is to ensure that individuals with developmental disabilities and their families design and can access services and supports that “promote self-determination, independence, productivity, and integration and inclusion” in community life. It is this purpose that grounds the Council’s comments on the State’s Plan to implement the Strengthening Career and Technical Education for the 21st Century (Perkins V) Act (P.L 115-224).

The reauthorization provides new opportunities to better align services and supports for individuals with disabilities to ensure they can truly access and benefit from opportunities for Career Technical Education (CTE) in a student-centered approach. CTE is an important and unique pathway to ensure individuals with disabilities develop the skills needed to be employed in competitive integrated employment (CIE), decrease poverty and move towards a life of economic self-sufficiency, independence and inclusion. SCDD commends the efforts of the California Workforce Pathways Joint Advisory Committee (CWPJAC) for its development of the Perkins V Plan but believes the Plan can be strengthened by including additional focus on individuals with disabilities and information about the strategies that CTE programs will use to ensure individuals with disabilities have equitable access to and are fully included and accounted for in CTE programs.

SCDD is pleased to see the Perkins V Plan recognize that “CTE can therefore no longer continue to exist as a separate educational alternative; it must be woven into the very fabric of our educational delivery system.” (p. 16). SCDD offers the following specific comments on the Perkins V Plan:

The Act uses the term “Special Populations” (20 U.S.C. 2302(48)) to define a group of individuals who are considered to be economically and socially disadvantaged in their opportunities to access and successfully complete CTE programs. Individuals with disabilities (20 U.S.C. 2302(28) citing 42 U.S.C. Section 12102) are listed as a distinct group of individuals included in the definition of “Special Populations.”

- Recommendation: Given that “individuals with disabilities” is the defined term in the Act, to ensure a consistent understanding of who the Act applies to, the Council believes that the Perkins V Plan should reference “individuals with disabilities” or “disabilities” and not “special needs” through-out the Plan (See pg. 46, 49, 76, 83, 106, 108, and 166).
The National Center for Education Statistics reports that in 2015-2016 the adjusted four-year cohort rate for all students in California was 93 percent, while the graduation rate for students with disabilities was 66 percent.¹ In 2016-2017, 74 percent of white students with disabilities who exited high school graduated with a regular diploma compared to 64 percent of black students with disabilities and 70 percent of Hispanic students with disabilities.²

- Recommendation: Given the data above, the Council believes the Perkins V Plan should include background data on individuals with disabilities in the discussion explaining the diversity of the State (p. 74). Furthermore, the Council believes that this section of the Plan should include additional data about the prevalence of disability, the outcomes associated with being an individual with a disability and a member of another special population.

California has seen minimal growth in the labor force participation rate and employment rate for individuals with disabilities since the recession. The American Community Survey (ACS) reports in 2017, only eight percent of people with disabilities were actively looking for work compared to 18 percent of working-age people without disabilities. The ACS also reports that in 2017, the employment rate of working-age people with disabilities in California was 36.8 percent compared to 77.3 percent of working-aged people without disabilities.³ In 2018, the Department of Developmental Services (DDS) reports that 16.2 percent of people with developmental disabilities who receive services through the Regional Centers are working. These numbers demonstrate the critical need to ensure individuals with disabilities are fully accounted for and included in all aspects of the Perkins V Plan.

- Recommendation: Given the data above, for individuals with disabilities, the Council believes the Perkins V Plan should include a goal to have a participation rate in CTE programs at the local agency and statewide level for individuals with disabilities similar to that of individuals without disabilities. To meet this goal, the Council encourages the CWPJAC to create goals for CTE programs to meet the needs of individuals with disabilities and to further increase their participation rate in these programs. The Council also believes that more robust cross-tabbed data needs to be collected regarding individuals with disabilities entry into and completion of CTE programs.

One of the barriers for individuals with disabilities in attaining or retaining CIE is having to work with multiple state agencies and providers to get access to services and supports. California has undertaken multiple initiatives to reduce these barriers. For example, to operationalize the Employment First Policy, the Departments of Education (CDE), Department of Developmental Services (DDS) and Department of Rehabilitation (DOR) have adopted the Competitive Integrated Employment Blueprint.⁴ Local Partnership Agreements (LPA) have been created to streamline services and supports needed for CIE between Regional Centers, DOR Districts and local education agencies (LEAs). The Perkins V Plan recognizes this agreement as an important step for students working towards CIE through CTE programs.

- Recommendation: The Council believes that the Perkins V Plan should more fully describe how CTE programs will coordinate services and supports with DOR and DDS (p. 107) and with the LPAs. In addition, the Plan recognizes that Special Education Local Planning Areas (SELPA) and Disabled Student Programs and

⁴ https://www.chhs.ca.gov/home/cie/
Services (DSPS) play an important role in ensuring equitable access to CTE programs, but the Council believes additional language is also needed on how SELPAs and DSPS can collaborate with CTE programs to align services and supports and ensure services are student-centered (p. 106). The Plan should also recognize that the Independent Living Centers play an important role in providing services and supports to individuals with disabilities who are not eligible for services from the Regional Centers.

Both Title II of Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act apply to CTE programs because they are operated by local government and/or receive federal financial assistance. The ADA provides that public entities, such as local and state government must not exclude individuals with qualified disabilities from participation in or be denied the benefits of services, programs and activities (42 U.S.C. 12131). Public entities are required to make reasonable modifications to policies, practices and procedures. For individuals with disabilities, this includes not only equitable access to the CTE program but also likely accommodations to benefit from the CTE program. CTE teachers and other professionals need to be provided appropriate training on working with individuals with disabilities to ensure equitable access and accommodations.

- Recommendation: Given these requirements, the Council believes that the Perkins V Plan should more fully describe how the State will ensure the provision of accommodations for individuals with disabilities in CTE programs. The Council also recommends that the Plan identify additional strategies that would prepare CTE teachers and other professionals to work with individuals with disabilities. For example, CTE teachers and other professionals should be provided professional development opportunities and technical assistance that include training on providing accommodations, universal design for learning and teaching diverse learners (p. 76 and p.114). Lastly, the Council believes the Plan should describe what action the State will take with CTE programs should they discover discriminatory practices during the State’s monitoring of CTE programs.

Thank you for considering the Council’s comments on the draft Perkins V Plan. The Council believes CTE programs provide additional opportunities for individuals with disabilities to attain or maintain CIE. The Council is interested in continuing to work to improve CTE programs for individuals with disabilities. If you have any questions or concerns, please contact our Deputy Director of Policy and Public Affairs, Cindy Smith at 916-799-8805 or cindy.smith@scdd.ca.gov.

Sincerely,

Maria Marquez, Chair
December 13, 2019

Cabinet Workgroup on Aging
Attn: Secretary Mark Ghaly, MD
California Health and Human Services Agency
1600 Ninth Street, Room 460
Sacramento, California 95814

Subject: Recommendations for a Senior and Disability Victimization Component of the Master Plan for Aging

Dear Members of the Cabinet Workgroup on Aging:

We wish to thank Governor Newsom, the Legislature, the members of the Master Plan for Aging Stakeholder Advisory Committee, Department of Aging Acting Director Kim McCoy Wade, and each of you for your commitment to developing a plan to accommodate and welcome the rapidly growing population of older Californians and of adults and children with disabilities.

We note that “increase prevention of elder abuse - both physical and financial” is the highest-ranked goal that California voters selected for the Master Plan for Aging. (California Statewide Voter Survey - Report on Results, Wallin Opinion Research, July 17, 2019).
Wide Extent of the Problem Nationally

What state law (Penal Code Section 368.6, enacted by SB 338 (Hueso) of 2019), now calls senior and disability victimization, including but going beyond elder and “dependent” adult abuse, is already an urgent and appalling problem. It includes these crimes committed against either older adults or people with disabilities: child abuse, sexual assault, domestic violence, human trafficking, hate crimes motivated by bias against people with disabilities including disabilities caused by aging, and homicide. The obstacles to justice include lack of reporting of these crimes to law enforcement agencies and the law enforcement agencies’ frequently inadequate response to the reports they do receive. Without timely and forceful action throughout the state, it can only get worse as the population of likely victims increases.

Several recent national studies found these shocking results:

*Abuse of People with Disabilities: Victims and Their Families Speak Out* (Nora Baladerian, Thomas F. Coleman and Jim Stream, Spectrum Institute Disability and Abuse Project, 2013) surveyed victims with disabilities, including disabilities caused by aging, and their families. Of the cases where victims reported the abuse to authorities, 52.9 percent said that nothing happened. According to the victims and family members surveyed, the number of alleged perpetrators arrested was 7.8 percent.

- *Incidents of Potential Abuse and Neglect at Skilled Nursing Facilities Were Not Always Reported and Investigated* (Office of the Inspector General, U.S. Department of Health and Human Services, June 2019) focused on abuse of nursing home residents who end up in emergency rooms. It looked at claims sent to Medicare in 2016 for treatment of head injuries, body bruises, bed sores and other diagnoses that might indicate physical abuse, sexual abuse or severe neglect. It found that nursing homes failed to report nearly one in five of these cases. Separately, it found that in five states where nursing home inspectors did investigate and substantiate cases of abuse, 97 percent were never reported to law enforcement as required by law.

- *CMS Could Use HHS Medicare Data to Identify Instances of Potential Abuse or Neglect* (Office of the Inspector General, U.S. Department of Health and Human Services, June 2019), looked at Medicare claims for the treatment of potential abuse or neglect of older adults, regardless of where it took place. The report projected that, of more than 30,000 potential cases, health care providers failed to report nearly a third of the incidents to law enforcement.

- *Criminal Victimization, 2017* (U.S. Bureau of Justice Statistics, December 2018) reported that persons with disabilities had a much higher rate of violent victimization (40.4 per 1,000 persons age 12 or older) than persons without disabilities (17.7 per 1,000). Persons with cognitive disabilities such as dementia, intellectual disabilities or mental illness experienced 76 violent victimizations per 1,000 persons age 12 or older, the highest rate among persons with any disability.

More broadly, a very large body of research stretching back for many years indicates that, throughout the country, persons with disabilities including disabilities caused by aging are victimized by violent crime at much higher rates than the general population and that the large majority of these crimes go unreported. (“Crimes Against Persons with Disabilities,” *Protecting Californians From Hate Crimes: A Progress Report*, Gregory deGiere, California Senate Office of Research, August 2004.)
Wide Extent of the Problem in California

The above national research reports are consistent with research and our experience here in California.

An evaluation of part of California’s Crime Victims with Disabilities Initiative (Crime Victims with Disabilities Specialists Program: A Report Prepared for the California Department of Mental Health, Valerie Jenness, University of California Irvine, and Nancy Naples, University of Connecticut, November 2003) stated the problem starkly:

“Across a variety of studies, the officially reported violence against persons with disabilities is simply alarming (Petersilia 2001). Moreover, the evidence suggests that officially reported violence against people with disabilities and criminal victimization of people with disabilities more generally is merely the tip of the iceberg as most violence against people with disabilities goes unreported. Lack of reporting occurs for a variety of reasons, including that the criminal justice system cannot--or will not--serve those with disabilities. Therefore, it is entirely appropriate to refer to people with disabilities who are victimized as ‘invisible victims’ (Sorenson 1997). As such, they have historically and in the present day been systematically denied access to justice via the criminal justice system (Petersilia 2003; Tysla 1998).”

The same California report found “numerous challenges” including:

- “Quite often there is a failure to pursue cases perceived to lack a credible victim (i.e., a victim with certain kinds of disabilities).”
- “Cases are dropped due to mistakes that occur during the investigation process.”
- “Cases are not investigated due to concerns over jurisdictional issues.”
- “Care facilities often deal with these types of crimes internally and may not create a safer environment for the victims who are often revictimized by other clients.”

Our experience since this 2003 study is that these problems persist.

In San Francisco in June 2019, the Department of Public Health reported that 23 patients of the Laguna Honda Hospital and Rehabilitation Center, ranging in age from 30 to around 100, suffered systematic verbal, physical and sexual abuse from 2016 to January 2019 at the hands of six employees who video recorded the abuse and exchanged the videos and photos by text messages. The estimate of victimized patients later was raised to 130. The San Francisco public health director pointed to what he called “a culture of silence” at the facility, where staff turn a blind eye to abuse. To date, no criminal charges of abuse or mandated reporters’ failure to report have been filed.

Our experience over many years indicates that such cultures of silence are common in some care facilities, particularly those serving residents with mental disabilities such as dementia, mental illness or intellectual disabilities, and that these cultures of silence often originate at the supervisory or management level.
Most recently, “The Rats Sensed She Was Going to Pass Away”: Elderly Often Face Neglect in California Care Homes that Exploit Workers (Jennifer Gollan, Reveal, Center for Investigative Reporting, September 18, 2019) found that some operators of senior board-and-care homes that violate labor laws and steal workers’ wages often also endanger or neglect their residents, sometimes with dire consequences.

Recommendations

We strongly recommend that the following 28 items be included in the Master Plan:

Upgrade enforcement by local law enforcement agencies

AB 2623 (Pan) of 2014 amended Penal Code Section 13515 to require all local law enforcement agencies to train their officers on the legal rights and remedies available to elder and “dependent” adult abuse victims. It also requires the Commission on Peace Officer Standards and Training (POST) to update its relevant training materials.

Virtually all law enforcement agencies adopt formal polices guiding their officers on enforcement of a wide variety of laws. In the past, most California law enforcement agencies’ elder and “dependent” adult abuse policies omitted any reference to Penal Code Sections 368 and 368.5, the relevant criminal statutes. As a result, many agencies viewed this abuse as a purely civil rather than criminal problem. SB 1181 (Hueso) of 2018 amended Penal Code Section 368.5 to require every local law enforcement agency to revise its policies to include the content of these sections making it clear that abuse is a criminal and not just a civil problem. We know of no accounting of whether all agencies have complied.

SB 338 (Hueso) of 2019 enacted Penal Code Section 368.6, the Senior and Disability Justice Act. The act includes a detailed though not comprehensive listing of items that every local law enforcement agency is required to adopt if it adopts or amends an elder and “dependent” adult abuse policy or a broader senior and disability victimization policy, including extensive required training, required investigation of every report of senior or disability victimization, detailed protocols for handling these crimes, and outreach to the older adult and disability communities to encourage reporting and cooperation with law enforcement.

(1) The Attorney General should notify law enforcement agencies of the requirements of PC 368.5 and PC 13515 and, after giving them adequate time to comply with these sections as amended, should survey them to determine whether they now comply.

(2) POST should review all its relevant training materials to ensure that they comply with PC 368.5 and PC 13515.

(3) POST should develop a model law enforcement agency policy including but not limited to the items listed in the Senior and Disability Justice Act, as Penal Code Section 368.6(c)(21) envisions.

(4) The Governor and Legislature should mandate that every local law enforcement agency adopt a senior and disability victimization policy as spelled out in the Senior and Disability Justice Act, including items added by POST. In legislating this mandate, the Legislature should review Section 368.6 and make whatever corrections and additions
experience indicates would be prudent. Because of its far-reaching effect, this is our highest priority recommendation for legislation.

(5) The Governor and Legislature should mandate that every county develop an interagency, interdisciplinary plan for attacking all aspects and senior and disability victimization, similar to but going beyond the San Diego County Elder and “Dependent” Adult Abuse Blueprint.

**Upgrade enforcement by the Department of Justice**

Abuse by licensed professionals, financial institutions and organized crime is often beyond the ability of local law enforcement agencies to police.

(6) The Governor and Legislature should make the Department of Justice the lead agency for combatting senior and disability victimization, including by authorizing DOJ to require local agencies to submit such information as the department may require concerning these crimes, such as copies of their formal policies and information on their officer training and outreach to the older adult and disability communities.

(7) The Attorney General should create, and the Governor and Legislature should fund, a senior and disability victimization unit in the Law Enforcement Division of the Department of Justice, incorporating the Bureau of MediCal Fraud and Elder Abuse. The new office should cooperate closely with state licensing agencies and with federal and other states’ law enforcement agencies.

(8) The Attorney General should revive and expand, and the Governor and Legislature should fund, Attorney General Lockyer’s “Face It, It’s a Crime” program for public information about and reporting of these crimes, both in and out of care facilities.

The statewide reporting portion of the program should include reporting by telephone, text, and Internet.

It should be explicit that anonymous reports are accepted and there should be a way for anonymous reporters to obtain report numbers to demonstrate that they made anonymous reports. While this should not relieve any mandated reporter of the duty to report fully, law enforcement, prosecutors and the courts should weigh any seriously mitigating facts including documented anonymous reports when they make decisions concerning arresting, prosecuting and sentencing mandated reporters who fail to fully report due to interference or well-founded fear of retaliation but instead make anonymous reports that result in stopping the abuse.

Local or state law enforcement agencies, in cooperation with adult protective services, local long term care ombudsman programs and other cooperating agencies where appropriate, should investigate every report, absent documented, unusual, compelling circumstances.

**Upgrade prosecution by district attorneys**

Cases involving victims or witnesses with cognitive or communications disabilities can be hard to prosecute and often require specially trained prosecutors, investigators and victim advocates.
District attorney’s offices without such specialists are at a disadvantage in prosecutions, including in providing victims with the services they need to recover from their victimization and be effective witnesses.

*Abused and Betrayed* (Joseph Shapiro, National Public Radio, January 8, 9, 16, 18 and 20 and June 25, 2018) reported that adults with intellectual disabilities are sexually assaulted at a rate seven times higher than those without disabilities. According to that report, there is reason to believe that predators target people with intellectual disabilities because they know they are seen as easily manipulated and will have difficulty testifying later. (This confirmed earlier California reports cited in “Crime Victims with Disabilities” (above), including one of a sexual predator overheard telling another to get a job in a developmental disability care facility where victims are “easy pickings.”) As a result, these crimes often go unrecognized, unprosecuted and unpunished.

AB 640 (Frazier) of 2019 amended Penal Code Section 13836 to cover sexual assault of people with developmental disabilities in the prosecutor training program developed by an Office of Emergency Services (OES) advisory committee.

(9) The Governor and Legislature should mandate and fund district attorney’s offices’ elder and disability victimization “vertical prosecution” units, staffed by trained attorneys, investigators and victim advocates. The mission of these units should be broad, and include: providing emergency assistance to victims including financial aid to stabilize finance abuse victims, adequate shelter for those at risk of homelessness due to their victimization, transportation to let them participate in the prosecution of their cases, and navigation to other available services; coordination with agencies and organizations that often learn of cases that would not otherwise reach the DAs, such as older adult and disability groups and service agencies, adult and child protective services, local long term care ombudsman programs, sexual assault and domestic violence agencies, and civil legal assistance services; ensuring prosecution of mandated reporters who fail to report and those who interfere or retaliate against mandated reporters, taking account of our Recommendation 8; and assistance with restorative justice sentencing.

(10) The Governor and Legislature should expand the prosecutors’ sexual assault training program created by PC 13836 to cover sexual assault of all persons with cognitive disabilities, including disabilities caused by aging, and to expand the membership of the OES advisory committee to include subject-matter experts selected by older adult and disability groups.

**Combat financial abuse of older adults and adults with disabilities**

Academic studies confirm the common-sense observations that aging affects human decision-making ability and that older adults as a result are more likely to fall prey to financial abuse of all sorts, including deceptive advertising, telemarketing and information technology victimization, and in-person con artists. For example:

- Approximately 35-40 percent of older adults studied were poor decision makers, displaying defective autonomic responses reminiscent of patients with traumatic brain injury. (*The Orbitofrontal Cortex, Real-World Decision Making, and Normal Aging*, Natalie L. Denberg et al, University of Iowa Hospitals and Clinics, 2008).
Financial literacy scores decline by 1 percent per year after age 60. Yet large declines in cognition and financial literacy have little effect on older adults’ confidence in their financial knowledge and almost no effect on their confidence in managing their finances. (*How Does Aging Affect Financial Decision Making?,* Keith Jacks Gamble, Patricia A. Boyle, Lei Yu and David A. Bennett, Center for Retirement Research at Boston College, 2015.)

The *True Link Report on Elder Financial Abuse* (*True Link Financial Advisors, 2015*) surveyed older Americans’ family caregivers. It extrapolated that financial abuse costs seniors more than $36 billion a year, 12 times earlier estimates. Even more shockingly, this report totally omits billions more lost to abuse by unscrupulous licensed professionals, financial institutions (particularly though reverse mortgage abuse), and organized crime (particularly financial abuse rings).

Here in California, hundreds of thousands of older adults and adults with disabilities are victimized by financial abusers every year. The loses to the individuals range from a few hundred dollars to millions. This abuse also puts a strain on the family members who have to use their assets for loved ones’ survival. Tragically, the instance of death goes up three-fold for those who are financially abused. Financial abuse is growing faster than any other type of abuse. Statewide, it has risen 176 percent since 2006. (*People Are Ripping Off LA Seniors At Alarming Rate - and It’s Making Them Sick*, Michelle Faust Raghavan, LAist, June 18, 2019, citing *SOC 242 - Adult Protective Services and County Block Grant Monthly Statistical Report*, California Department of Social Services, June 2019).

Too often, law enforcement tells a victim that their matter is “a civil case,” when, in fact, yes, it is a civil case, but also a criminal case that needs to be prosecuted. Because of difficulty in representing elders and people with disabilities who may be reluctant or incapable of aggressively pursuing civil cases, and the lack of clarity is some of the statutes, few civil litigators pursue financial abuse cases.

Existing elder and “dependent” adult abuse criminal law (Penal Code Section 368) prohibits “theft, embezzlement, forgery, fraud, and identity theft” but incudes no explicit prohibition of undue influence.

In cases of civil elder or “dependent” adult financial abuse, there is confusion as to what constitutes assisting a perpetrator.

Financial predators take full advantage of these omissions and unclarities to exploit older adults and adults with dementia or diminished capacity. This can leave no recourse for families who want to protect their loved ones’ property but who cannot find attorneys who will take their cases, cannot afford the few attorneys who are willing to try to litigate these cases, or are advised to that it is pointless to pursue legal action because their estates, after being partially or fully drained by scam artists, are no longer worth as much as their potential attorneys’ fees. These cases often involve sophisticated, organized schemes, including taking vulnerable adults across state lines to isolate them from their families and avoid legal process.

(11) The Governor and Legislature should amend Penal Code Section 368 to prohibit undue influence, which should be defined as “a person’s use of the person’s role, relationship or power to exploit or knowingly assist or cause another to exploit the trust, dependency, or fear of an elder or dependent adult, or uses the person’s role, relationship, or power to gain control deceptively over the decision making of the elder or dependent adult so that the free will of the elder/dependent adult has been removed. Such exploitation can be accomplished through deceiving, persuading, intimidating, threatening, isolation, fraudulent affection, or otherwise inducing the elder/dependent adult to act or fail to
act, in a manner detrimental to the elder’s or dependent adult’s interests resulting in inequity.”

(12) The Governor and Legislature should include in the finding in Welfare and Institutions Code Section 15600 that elders and “dependent” adults have a civil right to be free of the abuse, which California Elder Abuse and “Dependent” Adult Civil Protection Act (EADACPA, WIC Section 15600 et seq) prohibits, and that “abuse of an elder or dependent adult” as defined in WIC §15610.07 constitutes a violation of the victim’s civil rights.

(13) The Governor and Legislature should amend EADACPA to clarify that a person or entity shall be deemed to have taken, secreted, appropriated, obtained, or retained property for a wrongful use, or to have assisted such conduct, if, among other things, the person or entity takes, secretes, appropriates, obtains, or retains the property, or assists such conduct, and the person or entity knew or should have known that this conduct is likely to be harmful to the elder or “dependent” adult. They should also clarify that a person is deemed an assistor of financial abuse if that person knows or should know that their conduct is likely to be harmful, which is the standard used for the person who does the actual taking.

(14) The Attorney General should develop, and the Governor and the Legislature should fund, a comprehensive plan to combat financial abuse and other financial exploitation of older adults and adults with disabilities. The plan should include provisions to encourage supported decision-making, neither leaving those with limited capacity unprotected nor stripping them of their right to make their own decisions with whatever assistance they need.

**Combat anti-disability hate crimes**

Crimes committed in whole or in part because of victims’ actual or perceived disabilities, including disabilities caused by aging, are hate crimes under both California and federal laws. In practice, however, law enforcement officers rarely recognize these hate crimes.

A national survey of victims (*Hate Crime Victimization, 2004-2015*, U.S. Bureau of Justice Statistics, 2017) estimated 40,000 anti-disability hate crimes per year. (This figure is certainly an under-estimate. The survey omitted people with disabilities in hospices, nursing homes, group homes, hospitals, and other institutions.) Yet law enforcement agencies reported just 177 anti-disability hate crimes (*2018 Hate Crime Statistics*, Federal Bureau of Investigation, 2019), less than 0.5 percent of the estimated number based on the earlier victim survey. In California in 2018, law enforcement agencies reported just seven anti-disability hate crimes.

SB 1234 (Kuehl) of 2004 added disability as a protected characteristic under the hate crime law (PC 422.56(c)), required all state and local agencies to use the statutory definition of “hate crime” exclusively (PC 422.9), and required POST to develop a model hate crimes policy, which local law enforcement agencies are encouraged to adopt and state law enforcement agencies are required to adopt (PC 13519.6(c)).

PC 13023 mandates law enforcement agencies to submit to the Department of Justice such information on hate crimes as the Attorney General directs, including copies of their hate crime policies, if any, and their hate crime pamphlets mandated by PC 422.92. The last known time when DOJ surveyed law enforcement agencies and required submission of hate crime policies (though not pamphlets) was 2010. Of the 464 agencies surveyed, 44 did not respond, 76 reported they had no hate crime policies, and 39 submitted policies that did not comply with the requirement to use the statutory definition of “hate crime,” so just 65.7 percent submitted legally compliant policies. (*Hate Crime Survey Project*, Spring Robbins, Division of Law Enforcement, Department of Justice, October 12, 2010; and review of submitted policies, Jo Michael, Equality California, 2016).
A 2018 audit (Hate Crimes in California: Law Enforcement Has Not Adequately Identified, Reported or Responded to Hate Crimes, California State Auditor, May 2018) found that some law enforcement agencies failed to adequately carry out their responsibilities.

AB 1985 (Ting) of 2018 enacted Penal Code Section 422.87, including spelling out provisions for inclusion in law enforcement agencies’ hate crimes policies guiding officers on recognizing anti-disability hate crimes. POST this year updated its model policy to be consistent with the new law. We know of no evaluation of how many law enforcement agencies have adopted the updated POST model. The Department of Justice this week issued a bulletin to all California law enforcement agencies informing them of the requirements of AB 1985 (Information Bulletin No. 2019-DLE-08, December 9, 2019).

(15) The Attorney General should inform law enforcement agencies of the all provisions of the statutes listed above, not just those in AB 1985. After giving them adequate time to comply, the AG should survey the agencies pursuant to PC 13023 and require them to submit their hate crime policies, hate crime pamphlets, and information on officer hate crimes training. The Attorney General, in consultation with subject-matter experts including older adult, disability and civil rights groups, should determine the adequacy of the policies, pamphlets and training, including compliance with the statutes listed above and the audit recommendations.

(16) If the policies are inadequate or simply nonexistent, the Governor and Legislature should mandate all law enforcement agencies to adopt hate crime policies that include, but are not limited to, the statutory provisions, the audit recommendations, and any additional items determined by POST or the Legislature.

Improve victim services

AB 2877 (Thomson) of 2000 authorized the Crime Victims with Disabilities Initiative, administered by the Department of Mental Health. The bill allowed the department to use the Restitution Fund, generated from criminal fines, to address the problem of unequal protection for, and unequal services to, crime victims with disabilities, including disabilities caused by advanced age.

The program included grants in six counties for specialists on crime victims with disabilities. The specialists assisted victims and service providers in identifying and reporting crimes, and assisted the criminal justice system during investigations, prosecutions and trials.

The Crime Victims with Disabilities Specialists Program evaluation (cited above) found:

“When crimes against people with disabilities are reported, often there are limited community supports for them. For example, when a woman with a disability is a victim of domestic violence, there are no shelters available that will serve her if she is unable to perform chores and other duties associated with residency in a shelter.”

The same study evaluated the Crime Victims with Disabilities Specialists Program favorably:

“Overall the [program] was successful in increasing awareness of the needs of crime victims with disabilities, increasing the number of reports of crimes against people with disabilities, and increasing the number of prosecutions and convictions involving crime victims with disabilities.”

The university researchers who authored the evaluation recommended:

“Fund crime-victim specialists across the state in a way that recognizes training, time and emotional work involved in this unique form of service and advocacy.”
Unfortunately, though too typically, Governor Davis and the Legislature defunded the program and repealed the statutory authorization in the 2003 budget crisis -- before receiving the university researchers’ evaluation.

(17) The Governor and the Legislature should reauthorize and expand the Crime Victims with Disabilities Initiative, providing for specialists in every county. In reauthorizing and funding the program, the Governor and Legislature should take account of the evaluation’s recommendations.

(18) The Attorney General should determine whether victims services including domestic violence shelters are accessible to victims with disabilities including disabilities caused by aging. If they are not, the Governor and Legislature should mandate and fund them.

**Remedy mandated reporters’ failure to report**

According to reports we have received for many years, California mandated reporters often fail to meet their legal responsibilities to report, often because of factors such as: their employers’ interference in reporting, sometimes even with formal policies instructing them to report to managers instead of the required authorities; fear of retaliation by their employers, coworkers or others; well-founded beliefs that police will not take their reports seriously; and equally well-founded beliefs that police will not arrest them for failure to report, even if the police find out about the abuse from other sources.

The elder and “dependent” adult abuse mandated reporting statutes and child abuse reporting statutes prohibit supervisors or administrators from interfering in mandated reports. There is no such criminal statute covering coworkers or other persons and no known prohibition of retaliation for filing mandated reports.

The elder and “dependent” adult abuse reporting statutes and the child abuse reporting statutes are complicated and, in some cases, inconsistent with each other. The confusion may lead some mandated reporters to fail to report and law enforcement agencies to fail to enforce the reporting laws.

The *Crime Victims with Disabilities Specialists Program* report recommended:

“Develop and implement training programs for health care workers, educators, social workers, and bank personnel to improve the reporting and investigation of these crimes.”

(19) The Governor and Legislature should amend the elder and “dependent” adult abuse reporting statutes and the child abuse reporting statutes to prohibit interference or retaliation by any person.

(20) The Attorney General should evaluate the abuse reporting statutes. If necessary following that evaluation, the Governor and the Legislature should clarify and simplify them and make them consistent to the maximum extent possible.

(21) The Attorney General should develop, and the Governor and Legislature should mandate and fund, training for all mandated reporters. The training should include the anonymous reporting mechanism, penalties for nonreporting, and seriously mitigating facts we suggest in Recommendation 8.
Require criminal background checks of caretakers

Crime Victims with Disabilities Specialists Program also found:

“People with disabilities are victims of physical, sexual, and emotional abuse and neglect by their caretakers. However, [some] agencies serving them such as [Supported Living Services] are not required by law to conduct background investigations or fingerprinting of caregivers or other employees.”

(22) The Governor and the Legislature should mandate California Department of Justice criminal background checks for all caretakers of persons with disabilities including disabilities caused by aging, and all supervisors, managers, and other employees of service provider agencies, both licensed and unlicensed and both paid and unpaid, except for caretakers who are the person’s parent or who the person or the person’s parent selects, supervises, and has the legal authority and actual ability to remove. However, in cases of service provider agencies carrying out the state’s Lanterman Act responsibilities -- agencies that are constantly in danger of closing due to state under-funding -- the Governor and Legislature must fund the Department of Justice to cover the full costs of the background checks, not impose unfunded mandates on an already fragile system.

Improve end-of-life hospice care

Nationally between 2012 and 2016, over 80% of hospices serving dying patients had at least one deficiency; 20% had a serious deficiency, The problems included poor care planning, mismanagement of services and inadequate assessment of patients. (Deficiencies Pose Risks to Medicare Beneficiaries, U.S. Department of Health and Human Services Office of Inspector General Hospice, July 2019.) In a separate report from the same federal agency, a dozen examples of harm to patients were presented in gruesome detail. In one case, the hospice didn’t treat ulcers on a patient’s heels, and an amputation was required after gangrene set in. For another patient, “the hospice allowed maggots to develop around a beneficiary’s feeding tube.” (Safeguards Must Be Strengthened To Protect Medicare Hospice Beneficiaries From Harm, U.S. Department of Health and Human Services Office of Inspector General, July 2019.)

Here in California, some hospice residents also face serious problems in the last days of their lives, including: layers of fraud; poor staffing; broken care promises; avoidable suffering by hospice patients; lack of oversight and no accountability. Families seeking hospice care for their parents often encounter aggressive marketing, pressure by hospital staff, lack of comparative information to distinguish good hospice agencies from bad ones. (Steve Lopez, Los Angeles Times, January 19, February 16, February 24 and August 10, 2019).

(23) The Governor and Legislature should order a comprehensive evaluation of hospice care, taking account of the findings and recommendations of the two federal reports and leading to corrective legislation.

Ensure access

Lack of physical accessibility and necessary interpreters in effect means lacks access to justice for some older adults and people with disabilities.
(24) The Governor and Legislature should review all relevant statutes and amend them as necessary to ensure that all law enforcement agencies and other agencies serving older adults and people with disabilities are accessible to all victims and witnesses, and that everyone who needs access accommodations and interpreters (including sign language interpreters for deaf people) has them.

**Require data collection and evaluation**

*Crime Victims with Disabilities Specialists Program* found:

“There is a lack of systematic data collection efforts and systems that reveal the extent of the need for special services to crime victims with disabilities.”

Our own, generally unsuccessful efforts to find good data on senior and disability victimization indicate that, 16 years later, this has not changed.

The report recommended:

“Require law-enforcement agencies and district attorney’s offices to gather data on the number of crime victims with disabilities and the disposition of their cases, and reward agencies that dedicate adequate resources to pursing these crimes.”

(25) The Governor and the Legislature should mandate that law enforcement agencies report full, valid and reliable data on senior and disability victimization to the Department of Justice. This should include data on reports, arrests, disposition of cases, and demographics of victims by characteristics including age, disability, race and ethnicity.

(26) The Governor and Legislature should provide for evaluation and periodic reevaluation of the effectiveness of measures adopted in response to, at a minimum, the Master Plan’s senior and disability victimization component.

**Clarify terminology**

The multiple definitions of the terms “dependent” in the “dependent adult” and “dependent person” statutes are, for most practical purposes, virtually identical to the Penal Code definition of “disability” (PC 422.56(b)). However, the misleading word “dependent” has led many law enforcement officers, service providers and even abuse victims and their families to believe that the many people with disabilities who live independently are not protected by the elder and “dependent” adult or “dependent” person abuse laws.

The term “elder and dependent adult abuse,” too, is cumbersome, often leading to use of shorthand terms such as the misleadingly narrow “elder abuse” and the misleadingly broad “adult abuse.”

Finally, the term “dependent” demeans and insults the many people with disabilities who live independently.

(27) The Governor and Legislature should amend all relevant statutes to drop the term “dependent,” instead referring to “elder and disability abuse.” In amending the statutes,
the Governor and Legislature should make it explicit in the codes that the current legal definitions remain unchanged, merely changing the term defined, unless they determine that a change of any specific definition is needed.

**Ensure policy and budget transparency**

During budget crises, Governors and Legislatures often don’t just suspend some programs but also repeal their statutory authorization -- or suspend the programs’ authorizations in obscure sections of the budget bills that future Governors and Legislatures give little or no attention to reviewing, thus leaving the programs in the codes but having the same practical effect as outright repeal. Unfortunately, programs serving older adults and people with disabilities often have been the victims of these midnight, stealth repeals.

(28) For any parts of the Master Plan on Aging that the Governor and Legislature enact, future Governors and Legislatures should honor those enactments and not repeal them without full consideration not only of any temporary budget issues but also of longer-range policy and its effect on California’s older adults and people with disabilities. If they believe that a budget crisis requires them to suspend programs, they should amend those suspensions into the statutory authorization code sections and include sunset dates of no more than two years for the suspension. Such boilerplate language to be added to existing code sections might say:

“This section is suspended as of the effective date of the act that enacts this subdivision in the [years] session of the Legislature. This suspension shall end, and the section shall become effective, on [date] unless a later enacted statute extends that date.”

Thank you for your consideration of our recommendations.

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Report from the Statewide Self-Advocacy Network

Report by Councilmember Wesley Witherspoon

The Statewide Self-Advocacy Network (SSAN), a project of the State Council on Developmental Disabilities (SCDD), intent on connecting self-advocates, their communities and statewide organizations to increase leadership by persons with disabilities.

Recent Activity: The SSAN held their last meeting of 2019 on December 4-5, 2019 at the Crowne Plaza Northeast Sacramento.

Focus of Meeting:

DAY 1: Members received an update on efforts from SCDD to create a training curriculum using the 2016 CalOES Active Shooter Awareness Guidance train community members. Members discussed the workgroup structure. The SSAN workgroups are:

- Officers
- Membership Workgroup (membership workgroup will be appointed by the SSAN Chair)
- Employment Workgroup
- Legislative Workgroup
- Self-Determination Workgroup
- Newsletter/Communications Workgroup
- Youth Workgroup

Representatives from Disability Rights California gave a presentation on the Voters Choice Act and the importance of participating in the election process. Members reported on their activity in their community since the September SSAN meeting.
Day 2: Members reviewed and approved the 2018-2019 SSAN Annual Report. SCDD Executive Director Aaron Carruthers presented SSAN members with updates to the MOU between SSAN and SCDD based on input from the September SSAN meeting. Members approved the revisions to the MOU. The Chair requested that the final, signed copy of the MOU be included in the March 2020 SSAN packet. Allie Cannington, the Statewide Community Organizer for CFILC provided members with a presentation on the 2020 Census Count and CFILC efforts to encourage people with disabilities to take part in the Census. Many long-term services and supports (LTSS) programs rely on Census data to determine funding for their services. Members approved Volume 19 of the SSAN newsletter.

SSAN Leadership

Chair: Nicole Patterson, DDS Representative

Vice-Chair: Desiree Boykin, ARCA Representative

Secretary: Lisa Cooley, Sacramento Regional Representative

At the September SSAN meeting, the SSAN Chair suspended the workgroups for the rest of the year. As a result, only the SSAN Officers have met via teleconference for planning purposes.

Next Full SSAN Meeting: The next SSAN meeting will be on March 4th and 5th, 2020 at the Crowne Plaza Northeast in Sacramento.
AGENDA ITEM 7
INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Executive Director Report and Staff Reports

SCDD Executive Director Aaron Carruthers will provide Councilmembers with a report regarding recent Council activities. A hard copy of the report will be provided as a handout.

Additionally, the following staff reports have been included in the packet for review:

- Deputy Director of Administration report
- Deputy Director of Policy & Public Affairs report
- CRA/VAS update report
- Developmental Center closure update
- QA Project update report
Deputy Director of Administration Report

January 28, 2020

The Deputy Director of Administration exercises broad policy-making authority over the SCDD’s administrative functions including: personnel, fiscal, contracts, information technology and customer services to fulfill the strategic goals of the SCDD. Below is a summary of activities since the last Council meeting on November 14, 2019.

Fiscal/Administrative/Business Services/Information Technology

- Coordinated with SCDD Information Officer Lea Park-Kim and other staff to bring SCDD’s website into compliance with AB 434 website accessibility standards by January 1, 2020 deadline.
- Provided guidance to SCDD staff on the creation of accessible documents to be posted on the SCDD website.
- Met with California Department of Technology web design staff to begin the process to rebuild the SCDD website to give it a new look and feel. Information Officer Lea Park-Kim is leading this effort.
- Continued working with California Department of Technology to increase the internet connectivity bandwidth in all regional offices to enable videoconferencing and quicker upload and download of files and data to our server in Sacramento. Smaller field offices will have 10 MBPS speed and larger offices will have 20 MBPS speed.
- Continued to purchase ergonomically appropriate workstations from Prison Industries Authority and a certified small business vendor. The new workstations are being delivered and the Prison Industries Authority workstations are beginning to be delivered.
- Met with Department of General Services Real Estate Services and CDSS Business Services staff to consider options for long term stabilization of
continuously increasing space rental costs. These offices are:

- North State-Chico – Met with DGS planner in Chico in October.
- North Bay-Vallejo – Early stages of lease renewal.
- Central Coast-San Jose – Early stages of lease renewal.
- Sequoia-Fresno – Site search meeting with DGS planner in October.
- San Diego – Draft lease with lessor for approval
- Bay Area-Oakland – Working with CDSS on a long-term relocation with Community Care Licensing staff in South Oakland.

- Continued supervision of the Quality Assurance and Clients’ Rights Advocacy/Volunteer Advocacy Services programs with close collaboration with DDS.
- Communicated with DDS on the progress report for the Eliminating Disparities grant.
- Worked with Executive Director Carruthers, DDS Chief Deputy Directors and the CRA/VAS Program Manager on the future of the CRA/VAS staff affected by the closure of Sonoma and Fairview Developmental Centers.
- Continued monthly meetings with DDS QA Program staff and the SCDD QA Program Coordinator to discuss DDS’ current and future needs from SCDD in preparation for a new multi-year contract beginning in July 2020.
- Submitted the biennial State Level Accountability Act internal control report to the Department of Finance two weeks ahead of the submission deadline.
- Initiated the process with the Department of General Services Travel Program to convert to a more streamlined method for the booking of hotel rooms for SCDD members and staff.

**Personnel**

- Issued a statewide memo with the annual update of SCDD policies and employee certification.
- Submitted the 60-day response to the SPB compliance review report. SCDD performed very well with a few minor findings.
Report from Deputy Director, Policy and Public Affairs

The Deputy Director of Policy and Public Affairs is the lead person responsible for fulfilling the department’s federal and state mission for advocacy. The Deputy Director directs the department’s policy, advocacy and communication activities.

November 1, 2019 – January 15, 2020

- Reviewed, drafted and submitted SCDD’s comments on Career Technical Education State Plan.

- Began reviewing and drafting SCDD’s comments on Workforce Innovation and Opportunity Act (WIOA) Unified State Plan. Coordinated presentation in February by California Workforce Board to Employment First Committee on WIOA Plan.

- Drafted letter from Executive Director to Department of Rehabilitation (DOR) regarding Diversity Taskforce. Attended stakeholder meeting and provided input to DOR and other stakeholders on how to make the state a model employer for people with disabilities.

- Met multiple times with Disability Rights California (DRC) to discuss policy priorities in 2020. Drafted factsheet and bill language for two bills to co-sponsor with DRC in 2020. Provided input into other DRC proposals.

- Met with Member’s offices and Committee staff to discuss SCDD policy priorities related to employment and housing.

- Met with DRC and Department of Developmental Services (DDS) to discuss implementation of HCBS settings rule. Arranged for DDS to present to SAAC and/or SSAN.

- Participated in meeting with Executive Director, Council Chair and Vice-Chair to develop policy priorities and strategy for 2020. Developed branded materials with help of Communications Manager for Council to use in 2020.

- Continued to onboard Communications Manager. Posted position and conducted interviews for new Policy Analyst.

- Coordinated process to archive information on website and meeting with Deputy Director of Administration and Communications Manager to begin process of
revamping website. Met with California Department of Technology to begin the re-design of website. Oversaw the archival and deletion process to ensure the Council came into compliance with AB 434 (requiring website accessibility) by end of 2019.

- Supported Committee Specialist to prepare for Legislation and Public Policy and Employment First Committee meetings.

- Staffed Legislation and Public Policy Committee.

- Represented SCDD at Olmstead Advisory Committee meetings.

- Represented SCDD at Path Forward Collaborative meetings.

- Represented SCDD at Cross-Body Advisory Committee meeting.

- Communications Manager participated in the “Meet the Media” event at the Capitol and participated in a discussion with three Politico reporters. In the process of scheduling a one-on-one with one of the reporters to engage her in SCDD activities.

- Communications Manager drafted emails to send on Council list regarding State Plan Survey, Monthly Meetings and regarding potential Public Safety Power Shutoff event.

- Communications Manager continued to develop social media pages. Facebook post regarding the State Plan Survey was shared 37 times.
CRA / VAS

Clients' Rights Advocacy and Volunteer Advocacy Services

SCDD AT WORK INSIDE CALIFORNIA DEVELOPMENTAL CENTERS

Developmental Center/Community Facility Census as of January 1, 2020

Total Population: 262

<table>
<thead>
<tr>
<th>Developmental Center</th>
<th>Northern STAR</th>
<th>Porterville DC/Central STAR</th>
<th>Fairview DC/Southern STAR</th>
<th>Canyon Springs CF/Desert STAR</th>
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Program Activity for October, November and December 2019

**Northern STAR Unit and Former SDC individuals in the community**

SDC placed the last individual on December 17, 2018. SDC campus transferred to Dept of General Services from DDS on June 30, 2019. Northern STAR unit moved to the permanent residence in Vacaville. The CRA/VAS Program attended: 2 IPPs, 4 Special team conference, 2 day programming review, 12 community placement review meetings, 62 follow up contacts, 1 pre-admission for STAR. CRA serves all clients in the Northern STAR. VAS program will continue to serve individuals transitioned from SDC until June 2020.

**Canyon Springs Community Facility**

As of January 1, 6 clients are admitted to Desert STAR. CRA reviewed 1 denial of rights; 3 human rights/behavioral meetings, 7 IPPs, 5 transition meetings, facilitated 2 self-advocacy meetings, attended 12 Emerging Risk Notification; assisted 6 clients with court communication, provided 11 rights and other trainings staff. VAS attended 10 IPPs, 15 special meetings, 8 transition meetings, 16 community provider visits at CS, 10 community home observations, 4 self-advocacy trainings conducted. VAS Coordinator attended 20 professional groups and/or trainings in the community.

**Fairview Developmental Center**

CRA attended following meetings: 12 transition, 4 IPPs or special team meetings, 2 denial of rights, conducted 4 FDC employee rights trainings; 8 acute crisis meetings, 5 human rights/behavior support committees, 1 court hearing. CRA serves all clients in the STAR unit. VAS Coordinator and advocates attended following meetings: 26 transition, 2 denial of rights, 5 Human rights meetings, and facilitated a self-advocacy meeting.

**Porterville Developmental Center**

CRA attended 11 human rights meetings, 3 IPPs, 7 transition meetings, 2 People First/human rights meetings, 13 escort reviews, 5 denial of rights reviews, 18 court appearances, 1 handcuff debriefing, provided 4 staff trainings, submitted 3 incident reports. VAS attended at PDC and in the community: 8 IPPs, 69 transition meetings, 5 self-advocacy meetings, 1 handcuff debriefing, 1 escort review, 1 recruitment fair, 16 court hearings. A CRA/VAS team member attends every transition meeting for PDC clients.

**Program Team Members**

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<tr>
<th>North Star - Sonoma DC</th>
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<tr>
<td>Ross Long, CRA/VAS</td>
<td>Erika Flores, CRA</td>
<td>Laurie St. Pierre CRA/VAS</td>
<td>Julie Hillstead, VAS</td>
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<tr>
<td>Michele Sloane, OT</td>
<td>Judi Muirhead, VAS</td>
<td>Connie Wilson, OT</td>
<td>Robbin Puccio, CRA</td>
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Holly R. Bins, Program Manager

January 2020
Clients’ Rights Advocate and Volunteer Advocacy Services

Developmental Center Closure Update
January 2020

Community Transition Numbers for 2019

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<th>Facility</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
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<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
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*Canyon Springs Community Facility and Porterville Developmental Center Secure Treatment Area are not scheduled for closure. The Porterville Developmental Center General Treatment Area is scheduled to close mid-January 2020. Fairview Developmental Center is tentatively scheduled to close by January 31, 2020.

Developmental Center, Community Facility, STAR Unit Population as of January 1, 2020

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<th>GTA* (ICF)</th>
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</tr>
<tr>
<td>Porterville DC/</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>201</td>
<td>1</td>
<td>203</td>
</tr>
<tr>
<td>Central STAR</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern STAR</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>TOTAL</td>
<td>47</td>
<td>0</td>
<td>14</td>
<td>201</td>
<td>1</td>
<td>262</td>
</tr>
</tbody>
</table>

*Porterville Developmental Center is the only DDS operated facility that has a secured treatment area (STA) and a general treatment area (GTA). The STAR units remain on closed facility grounds until new community homes are developed and ready for operation.
Developmental Center Closures – Past and Present

Facility | Projected Closure Date and Land Use
Sonoma Developmental Center | Closed December 17, 2018 (site transferred to Department of General Services on July 1, 2019)
Fairview Developmental Center | January 31, 2020
located in Costa Mesa
Porterville Developmental Center | January 15, 2020 (General Treatment Area only)
Canyon Springs Community Facility | No proposed closure date
located in Cathedral City
Lanterman Developmental Center | Closed 2014 (Site is now part of Cal Poly, Pomona)
Agnews Developmental Center | Closed 2009 (Sold to corporations and City of San Jose)
Sierra Vista Community Facility | Closed 2009
Camarillo Developmental Center | Closed 1997 (Site is now Cal State Univ, Channel Islands)
Stockton Developmental Center | Closed 1996 (Site is now part of Cal State, Stanislaus)

California Department of Public Health (CDPH) and Centers for Medicare & Medicaid Services (CMS)

<table>
<thead>
<tr>
<th>Facility</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canyon Springs</td>
<td>CDPH surveyed in August 2019. No conditions out.</td>
</tr>
<tr>
<td>Fairview</td>
<td>CMS settlement agreement extended to December 31 2019 CDPH surveyed in September 2019. No conditions out.</td>
</tr>
<tr>
<td>Porterville</td>
<td>CMS settlement agreement extended to December 31 2019 for GTA ICF</td>
</tr>
</tbody>
</table>

Porterville and Fairview Certified Unit Population Projections

The projections below establish the maximum permissible client census eligible for federal funding in the PDC and FDC certified units as of the first calendar day of the listed month. Federal Financial Participation is only permissible for clients on the Client List as of June 27, 2016. No Federal Financial Participation can be sought for the number of clients that exceed the projections below, even if the clients that exceed the census limits below are on the Client List as of June 27, 2016.

<table>
<thead>
<tr>
<th>Monthly Census Maximum Per CMS Agreement</th>
<th>Porterville DC General Treatment Area ICF Maximum Census</th>
<th>Actual ICF Census</th>
<th>Fairview DC ICF Maximum Census</th>
<th>Actual ICF Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2016</td>
<td>105</td>
<td>104</td>
<td>136</td>
<td>128</td>
</tr>
<tr>
<td>July 2017</td>
<td>82</td>
<td>80</td>
<td>106</td>
<td>91</td>
</tr>
<tr>
<td>July 2018</td>
<td>61</td>
<td>57</td>
<td>57</td>
<td>56</td>
</tr>
<tr>
<td>July 2019</td>
<td>39</td>
<td>20</td>
<td>5</td>
<td>26</td>
</tr>
</tbody>
</table>
SCDD Clients’ Rights Advocate (CRA) current observations inside the DC/CF

<table>
<thead>
<tr>
<th>Location</th>
<th>Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canyon Springs</td>
<td>Desert STAR crisis unit has six clients. CRA provides initial service and transition collaboration with team. CS staff turnover impacts the communication and programming efficacy for clients. CRA collaborating with RCs regarding improved transition activity and communication. CRA is advocating for more immersive community activities for clients in transition process which better prepares them for community living.</td>
</tr>
<tr>
<td>Fairview</td>
<td>FDC staff recalled to support three consumers where placements were delayed. FDC increasing use of registry staff and utilizing personnel from other DCs to fill vacancies. Some registry staff are connecting and planning for continued employment with I/DD community.</td>
</tr>
<tr>
<td>Porterville</td>
<td>CRA continues to advocate for successful transitions for GTA and STA individuals. Tulare County DA imposing more restrictive requirements than clients need. Advocacy provided with successful outcomes. Lack of least restrictive environment for female STA clients that include newer units include single bedroom and bathroom that their male counterparts enjoy. PDC administration reviewing building layouts. New local judge appointed in Tulare County. CRA is collaborating with DDS for tour and sit down. Three appeals initiated in September. No response received from DDS as of this report. CRA is facilitating relationships with Child Welfare Services and probation due to opening of adolescent unit for Central STAR.</td>
</tr>
<tr>
<td>Sonoma</td>
<td>Acting CRA (VAS Coordinator) providing clients’ rights assistance including attendance in IPPs and transition planning meetings for individuals residing in the Northern STAR unit at Vacaville. The unit houses four individuals at this time.</td>
</tr>
</tbody>
</table>

SCDD Volunteer Advocacy Services (VAS)

The VAS Project serves approximately 25% of the individuals residing in the DC/CFs. A volunteer advocate or the VAS Project Coordinator provides direct advocacy services for twelve months post placement.

<table>
<thead>
<tr>
<th>Location</th>
<th>Observation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canyon</td>
<td>VAS program has 13 Volunteer Advocates serving 38 individuals at CS and 7 in the community. VAS Coordinator advocated for greater communication with clients post transition. VAS advocates for meaningful excursions and more immediate access to trust monies. VAS continues to collaborate with team for client access NA services in the community. VAS is collaborating with teams for RC transfer and immigration status.</td>
</tr>
<tr>
<td>Location</td>
<td>Details</td>
</tr>
<tr>
<td>----------</td>
<td>---------</td>
</tr>
<tr>
<td>Fairview</td>
<td>VAS Coordinator and advocates continue to advocate for notification for the project and significant others of changes in condition of clients in the community. VAS continues to advocate individualized transition planning as DDS pursues closure.</td>
</tr>
<tr>
<td>Porterville</td>
<td>VAS attends every transition meeting and IPP for all GTA clients within the project. Individuals leaving the GTA are experiencing delays in transition due to slowed construction and licensing of community homes. Tentative transition dates were set and communicated to clients despite assurance of placement availability. VAS advocating individualized transition planning and appealed decisions that were not in best interest of clients. Advocates witness lack of consistent delivery of services in the GTA due to seasoned staff securing positions in the Secure Treatment Area and other agencies. VAS continues to advocate for CIE for two individuals waiting for employment opportunities in the community.</td>
</tr>
<tr>
<td>Sonoma</td>
<td>The VAS program serves individuals for twelve months post placement. SDC closed in December 2018 thus the VAS program would end January 2020. DDS and SCDD negotiated an extension to serve individuals for six more months. VAS performed over 75 contacts and/or visits of clients who transitioned from SDC this reporting period. Day program services and health coverage continue to require extensive oversight for quality and continuity for people transitioning from SDC to the community.</td>
</tr>
</tbody>
</table>
Adult Family Survey (AFS) and Family Guardian Survey (FGS) Cycle

In December, SCDD began mailing surveys to families with an adult family member receiving at least one regional center funded service. The Adult Family Survey (AFS) is mailed to those with a family member living at home, while the Family Guardian Survey (FGS) is mailed to those with a family member living outside the family home. We expect to mail approximately 110,000 surveys.

While December marks the start of surveys being mailed, families have had the opportunity to complete their surveys online since mid-October. To date, over 4,000 families have already taken the opportunity to enter their responses online. This option is currently available only in English. However, DDS has plans to offer more languages in future cycles.

The AFS/FGS collection cycle ends July 31, 2020

For more information on the Quality Assessment Project or to complete your survey online, please visit www.scdd.ca.gov/qap

Mover Longitudinal Study (MLS)

SCDD continues to implement the Mover Longitudinal Study (MLS), interviewing individuals face to face who have moved out of the Developmental Center from 2015 to the present. Initially, movers were to be followed for two years but the MLS has been extended and Movers will be surveyed for 5 years after they leave the Developmental Center. Individuals are surveyed 3 months, 6 months, 1 year, 2 years, 3 years, 4 years and 5 years after the date they move into the community.

At present, 617 movers living in 28 different counties across California are in enrolled in the study. 1,849 surveys have been conducted for those currently enrolled.

When individuals enrolled in the study have family which have been identified by regional center, those families receive the Family Guardian Survey (FGS) at the same scheduled periods as the face to face interviews. To date, SCDD has received 444 Family Guardian Surveys through the MLS.
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JANUARY 28, 2020

AGENDA ITEM 8
INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

2020-2021 Governor’s Proposed Budget

The Health and Human Services Agency (HHS) and the Department of Developmental Services (DDS) will present highlights from the 2020-2021 Governor’s Proposed Budget. A 27-page accessible summary of funding changes and updates can be found at http://www.ebudget.ca.gov/2020-21/pdf/BudgetSummary/HealthandHumanServices.pdf. A hard copy of this document will also be available at the meeting.

Attachments
- Department of Developmental Services Governor’s Budget Highlights
Department of Developmental Services

Governor’s Budget Highlights

Gavin Newsom
Governor
State of California

Mark Ghaly MD, MPH
Secretary
California Health and Human Services Agency

Nancy Bargmann
Director
Department of Developmental Services

January 2020
The Department of Developmental Services (Department) is responsible for administering the Lanterman Developmental Disabilities Services Act (Lanterman Act). The Lanterman Act provides for the coordination and provision of services and supports to enable people with developmental disabilities to lead more independent, productive, and integrated lives. The Early Start Program provides for the delivery of services to infants and toddlers at risk of having a developmental disability. The Department carries out its responsibilities through contracts with 21 community-based, non-profit corporations known as regional centers, two state-operated developmental centers, one state-operated community facility, and Stabilization, Training, Assistance and Reintegration (STAR) homes.

The number of individuals served by regional centers (consumers) is expected to increase from 350,047 in the current year to 368,622 in 2020-21. The ending population of individuals in state-operated residential facilities is estimated to be 302 on July 1, 2020.

GOVERNOR’S BUDGET SUMMARY
The 2020-21 Governor’s Budget includes $9.2 billion total funds ($5.7 billion General Fund [GF]) for the Department in 2020-21; a net increase of $1.0 billion ($624.6 million GF) over the updated 2019-20 budget.

<table>
<thead>
<tr>
<th>FUNDING SUMMARY</th>
<th>2019-20</th>
<th>2020-21</th>
<th>Difference</th>
<th>Percentage Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>BUDGET SUMMARY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Services</td>
<td>$7,735,113</td>
<td>$8,751,047</td>
<td>$1,015,934</td>
<td>13.1%</td>
</tr>
<tr>
<td>State Operated Facilities</td>
<td>326,381</td>
<td>300,186</td>
<td>-26,195</td>
<td>-8.0%</td>
</tr>
<tr>
<td>Headquarters Support</td>
<td>97,881</td>
<td>118,220</td>
<td>20,339</td>
<td>20.8%</td>
</tr>
<tr>
<td><strong>TOTALS, ALL PROGRAMS</strong></td>
<td>$8,159,375</td>
<td>$9,169,453</td>
<td>$1,010,079</td>
<td>12.4%</td>
</tr>
<tr>
<td>GENERAL FUND</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Services</td>
<td>$4,686,900</td>
<td>$5,314,052</td>
<td>$627,152</td>
<td>13.4%</td>
</tr>
<tr>
<td>State Operated Facilities</td>
<td>283,828</td>
<td>267,126</td>
<td>-16,702</td>
<td>-5.9%</td>
</tr>
<tr>
<td>Headquarters Support</td>
<td>63,372</td>
<td>74,495</td>
<td>11,123</td>
<td>17.6%</td>
</tr>
<tr>
<td><strong>GF TOTAL, ALL PROGRAMS</strong></td>
<td>$5,034,100</td>
<td>$5,655,673</td>
<td>$621,573</td>
<td>12.3%</td>
</tr>
</tbody>
</table>

For more detail, please refer to the Program and Funding Summary on page 7.
COMMUNITY SERVICES PROGRAM

2019-20
The 2019-20 updated Regional Center budget includes $7.7 billion ($4.7 billion GF), which is a net decrease of $63.0 million ($14.3 million GF), or 0.81 percent, as compared to the enacted budget. The primary driver of the decrease is attributed to expenditures for the January 1, 2019 Senate Bill (SB) 3 minimum wage increase coming in lower than originally estimated.

There is a net decrease of 114 consumers in the updated 2019-20 projections due to a slight decrease in the number of individuals served in the Early Start program.

Regional Center Operations
The Operations budget reflects a net increase of $879,000 ($27.4 million GF) over the enacted budget. The main driver for this increase is $1.1 million in one-time funding for regional centers to assist consumers who may be eligible for increased benefits due to the expansion of CalFresh for Supplemental Security Income/State Supplementary Payment (SSI/SSP) recipients.

Purchase of Service Caseload Growth and Utilization
Updated Purchase of Service (POS) expenditures reflect a net decrease of $71.0 million ($48.0 million GF), or a 1.08 percent decrease, as compared to the enacted budget. The decrease is primarily attributed to expenditures for the January 1, 2019 SB 3 minimum wage increase coming in lower than originally estimated. The estimated increase in the Community Care Facilities (CCF) category reflected below is mostly related to expenditures for individuals who have moved from Developmental Centers.

Policy - POS
There is a net increase of $7.1 million ($6.3 million GF) in policy related expenditures for 2019-20 as compared to the enacted budget. The main drivers are:

**SB 3 minimum wage, January 1, 2020 ($12.00 to $13.00 per hour)**
Increase of $5.9 million ($4.1 million GF).

**STAR Homes**
Transfer of $3.0 million GF from State Operations to Local Assistance for the development of the two community STAR homes.

2020-21
The 2020-21 Governor’s Budget includes $8.8 billion ($5.3 billion GF) which is a net increase of $1.0 billion ($627.2 million GF) as compared to the updated current year budget.

The estimated 2020-21 population is 368,622, reflecting an increase of 18,575 (5.3 percent), as compared to the updated current year budget. This increased projection is comprised of 14,455 active consumers and 4,120 individuals receiving Early Start services.
Regional Center Operations
The 2020-21 regional center operation reflects a net increase of $40.1 million ($33.1 million GF), or a 5.46 percent, as compared to the updated current year budget. The increase is mainly attributable to the projected increase in population.

Policy - Regional Center Operations
There is a net increase of $17.3 million as compared to updated current year budget. The 2020-21 Governor’s Budget includes the following proposed policy revisions:

Enhanced Caseload Ratios for Consumers Ages Three and Four
Increase of $16.5 million ($11.2 million GF) to provide a 1:45 service coordinator to consumer caseload ratio for consumers who are three and four years old.

Specialized Home Monitoring
Increase of $746,000 ($508,000 GF) to provide required monitoring of additional specialized homes that will become available in 2020-21.

POS Caseload Growth and Utilization
POS caseload and Utilization reflects an increase of $420.3 million ($263.4 million GF), or 6.49 percent increase, as compared to the updated current year budget. The increase is primarily attributable to expenditure growth in the following categories: Community Care Facilities, Support Services, In-Home Respite and Miscellaneous. Estimated expenditure growth in Support Services is mainly due to growth in Supported Living Services, Personal Assistance, and Community Integration Training Program. For Support Services overall, 60 percent of the increase is due to higher caseload and 40 percent reflects higher per capita expenditures.

Policy - POS
There is a net increase of $538.2 million ($319.0 million GF) as compared to the updated current year budget for the following items:

Community Crisis Homes for Children
Decrease of $4.5 million GF due to one-time start-up funding.

Development of STAR Homes
Decrease of $3.0 million GF due to one-time start-up funding.

Enhanced Behavioral Supports Homes (EBSH) with Delayed Egress and Secured Perimeter (DESP)
Increase of $7.5 million GF to develop five EBSHs with DESP to reduce reliance on restrictive settings and provide opportunities for individuals to move to the community, with appropriate and necessary supports.

Electronic Visit Verification Penalty Payment
Increase of $5.1 million GF in estimated federal financial payment penalties for applicable services.
Performance Incentive Program
Increase of $78.0 million ($60.0 million GF) to establish a Performance Incentive Program for Developmental Services administered through Regional Centers. The Performance Incentive Program will align with each Regional Center’s performance contract and require Regional Centers to meet an advanced tier of performance measures and outcomes to receive incentive payments.

Provider Supplemental Rate Increase (Effective January 2020)
Increase of $206.2 million ($124.5 million GF) reflects a full year impact compared to a half year in the current year.

Additional Provider Supplemental Rate Increase (Effective January 2021)
Increase of $18 million ($10.8 million GF) to increase rates for three additional services: Early Start Specialized Therapeutic Services, Independent Living Program, and Infant Development Program. The budget assumes the rate increases will be effective January 2021 upon approval of federal funding.

SB 3 Minimum Wage, January 1, 2020 ($12.00 to $13.00 per hour)
Increase of $103.8 million ($53.2 million GF) reflects a full year impact compared to a half year in the current year.

SB 3 Minimum Wage, January 1, 2021 ($13.00 to $14.00 per hour)
Increase of $120.3 million ($61.4 million GF) reflects a projected half-year impact due to the increased minimum wage.

Systemic, Therapeutic, Assessment, Resources and Treatment Training (START) Training
Increase of $4.5 million ($2.6 million GF) to support individuals in their current residential arrangement and prevent disruptions and admissions into more restrictive settings, such as Institutions for Mental Diseases, out-of-state services, acute psychiatric settings, Community Crisis Homes and STAR services through the provision of 24-hour crisis services and planning, and by providing training to families, direct support staff, and local partners (e.g., police, hospital staff, teachers) on person-centered, trauma-informed, and evidence-based support services for individuals with co-occurring developmental disabilities and mental health needs.

Uniform Holiday Schedule
Increase of $2.4 million ($1.4 million GF) to reflect actual expenditures through 2018-19.
STATE OPERATED FACILITIES PROGRAM

2019-20
The ending population on July 1, 2019 was 363 individuals. The Department projects an ending population of 302 individuals on June 30, 2020.

The 2020-21 Governor’s Budget includes $326.4 million ($283.8 million GF), which is a net increase of $5.0 million ($4.1 million GF). The net increase is a combination of the following adjustments:

Operations Expenditures
Decrease of $3.0 million GF reflecting a budget revision transferring $3.0 million from State Operations to Local Assistance for the development of the two community STAR homes in Central California.

Employee Compensation and Retirement
Increase of $8 million ($7.1 million GF) for compensation and retirement adjustments approved through the collective bargaining process.

2020-21
The Governor’s Budget includes $300.1 million ($267.1 million GF), a decrease of $26.2 million ($16.7 million GF) as compared to the updated current year budget. The decrease reflects the following adjustments:

Operations Expenditures
Decrease of $24.7 million ($15.6 million GF) and is comprised of a $19.8 million reduction in Personal Services and $4.9 million reduction in Operating Expenses and Equipment.

• Increase of $8.9 million GF and 72.3 positions for the Secured Treatment Program (STP) at Porterville to temporarily expand bed capacity from 211 to 231 beds. The Department will add one Intermediate Care Facility (ICF) Unit of 20-beds. The STP bed capacity would return to 211 by July 1, 2024.
• Increase of $11.9 million GF and 54.0 positions to extend the warm-shutdown period at Fairview DC through June 30, 2021. The Department of General Services is in the process of completing a site assessment to inform the disposition of the property.
• Increase of $1.1 million GF for 8.0 positions for the South Coast Regional Project (SCRP). The SCRP will continue to support the transition activities of all individuals from state operated facilities.

Employee Compensation and Retirement
Decrease of $1.5 million ($1.1 million GF) for employee compensation and retirement adjustments approved through the collective bargaining process.

CAPITAL OUTLAY
The Governor’s Budget does not include a proposal for capital outlay funds in 2020-21.
DEFERRED MAINTENANCE
The Governor’s Budget does not include funding for deferred maintenance in 2020-21.

HEADQUARTERS

2019-20
The 2020-21 Governor’s Budget includes $97.9 million ($63.4 million GF), a net increase of $5.4 million ($4.0 million GF). The increase is comprised of compensation and retirement adjustments approved through the collective bargaining process and included Item 9800 – Employee Compensation Adjustments; an increase in funding authority for Community State Staff Program; and DGS Reimbursement for O Street Office Cleanup.

2020-21
The 2020-21 Governor’s Budget includes $118.2 million ($74.5 million GF) for Headquarters, an increase of $20.3 million ($11.2 million GF) compared to the updated current year. The net increase is comprised of employee compensation and retirement adjustments approved through the collective bargaining process, included Item 9800- Employee Compensation Adjustments and five Budget Change Proposals as detailed below:

Southern California Headquarters Office
$2.0 million ($1.6 million GF) for new leased space to support approximately 100 permanent positions in Costa Mesa/Orange County, CA in 2020-21. Of this request, $1.2 million ($1.0 million GF) is ongoing.

Information Security Office
$0.3 million ($0.2 million GF) and two (2.0) Information Technology Specialist I positions to support workload related to the highest assessed information security and cybersecurity vulnerabilities.

Information Technology Data and Planning
$2.2 million ($1.9 million GF) and four (4.0) permanent Information Technology Specialist II positions, resources equivalent to three (3.0) positions on a two-year limited term basis and supporting resources for modernization of the Information Technology Division organizational infrastructure to ensure support for increasingly complex technology and critical data needs of the Department’s programs.

Uniform Fiscal System (UFS) Modernization
$1.4 million ($1.3 million GF) and two (2.0) positions on a two-year limited term basis, and related consulting resources to support planning for the UFS replacement project.

Community State Staff Program (CSSP) Reimbursement
$9.7 million increase in reimbursement authority, for temporary help expenditures related to the continuing operation of the CSSP.
# 2020 Governor’s Budget
Program and Funding Summary
(Dollars in Thousands)

<table>
<thead>
<tr>
<th>Community Services Program</th>
<th>2019-20*</th>
<th>2020-21</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regional Centers</td>
<td>$7,735,113</td>
<td>$8,751,047</td>
<td>$1,015,934</td>
</tr>
<tr>
<td>Totals, Community Services</td>
<td>$7,735,113</td>
<td>$8,751,047</td>
<td>$1,015,934</td>
</tr>
<tr>
<td>General Fund</td>
<td>$4,686,900</td>
<td>$5,314,052</td>
<td>$627,152</td>
</tr>
<tr>
<td>Program Development Fund (PDF)</td>
<td>2,242</td>
<td>2,280</td>
<td>38</td>
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<tr>
<td>Developmental Disabilities Svs Acct</td>
<td>150</td>
<td>150</td>
<td>0</td>
</tr>
<tr>
<td>Federal Trust Fund</td>
<td>53,580</td>
<td>53,580</td>
<td>0</td>
</tr>
<tr>
<td>Reimbursements</td>
<td>2,991,501</td>
<td>3,360,245</td>
<td>388,744</td>
</tr>
<tr>
<td>Mental Health Services Fund</td>
<td>740</td>
<td>740</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>State Operated Facilities Program</th>
<th>2019-20*</th>
<th>2020-21</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Services</td>
<td>$273,954</td>
<td>$252,658</td>
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</tr>
<tr>
<td>Operating Expense &amp; Equipment</td>
<td>52,426</td>
<td>47,528</td>
<td>-4,898</td>
</tr>
<tr>
<td>Total, State Operated Facilities</td>
<td>$326,381</td>
<td>$300,186</td>
<td>-$26,195</td>
</tr>
<tr>
<td>General Fund</td>
<td>$283,828</td>
<td>$267,126</td>
<td>-$16,702</td>
</tr>
<tr>
<td>Federal Trust Fund</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Lottery Education Fund</td>
<td>192</td>
<td>192</td>
<td>0</td>
</tr>
<tr>
<td>Reimbursements</td>
<td>42,361</td>
<td>32,868</td>
<td>-9,493</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Headquarters Support</th>
<th>2019-20*</th>
<th>2020-21</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal Services</td>
<td>70,183</td>
<td>83,465</td>
<td>8,282</td>
</tr>
<tr>
<td>Operating Expense &amp; Equipment</td>
<td>27,698</td>
<td>34,755</td>
<td>6,824</td>
</tr>
<tr>
<td>Total, Headquarters Support</td>
<td>$97,881</td>
<td>$118,220</td>
<td>$15,106</td>
</tr>
<tr>
<td>General Fund</td>
<td>$63,372</td>
<td>$74,495</td>
<td>$10,890</td>
</tr>
<tr>
<td>Federal Trust Fund</td>
<td>2,797</td>
<td>2,723</td>
<td>-74</td>
</tr>
<tr>
<td>PDF</td>
<td>404</td>
<td>404</td>
<td>0</td>
</tr>
<tr>
<td>Reimbursements</td>
<td>30,817</td>
<td>40,107</td>
<td>4,290</td>
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<tr>
<td>Mental Health Services Fund</td>
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<td>$9,169,453</td>
<td>$1,004,845</td>
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<th>Total Funding</th>
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*Total Expenditures do not reflect the statewide item for Employee Retention Incentives of $1.5 million in 2019-20 and $15.7 million in 2020-21. The incentives were added by the 2016 Budget Act and displayed as a Carryover/Re-appropriation in the Governor's Budget Galley.
OVERVIEW

As it sets its strategic goals for 2020, the Council can capitalize on several strengths to set a bold agenda. First, the current Council members will largely be the same Council working together for the next 3 to 5 years. Also, the vision of the Council and its leadership is looking to the frontiers of advocacy to make a mark and leave a legacy. Additionally, the Council as a body is positioned to drive advocacy on new items while providing expertise on many critical efforts that are currently underway. These strengths allow the Council to set goals that can take multiple years to accomplish, including both immediate and long-term targets.

During the Fall of 2018, the legislative and employment committees set priorities for the upcoming two-year legislative session. During the Fall of 2019, these committees used the priorities to specify bills the Council could possibly sponsor. In November 2019, the Council revised the Policy Platform (attached). From this work and these documents, the Chair and Vice Chair met with the Executive Director and Deputy Director of Public Policy to identify specific policy changes in three areas: housing, employment, and safety that were then worked into the revised 2020 Policy Priorities (attached). These are specific Council and headquarters focused areas of the State Plan.

The following is a list of topics where the Council will lead and where the Council will join others by providing expertise. The revised 2020 Policy Priorities reflects both leading and side-by-side efforts. These ambitious goals will leave SCDD capacity to support approximately 10 bills sponsored by others.
LEADING THE WAY

The Council has identified three priority areas to drive change around: housing, employment, and safety.

Lead on Housing

The number one recommendation in the Council’s 2018 Statewide Strategic Housing Framework is to identify dedicated funding for housing for people with IDD. The Framework shows that we need 20,000 new units. A $400 million IDD housing fund would provide gap funding for approximately 2,285 units, or meet 11% of the need.

The criteria for the Multifamily Housing Program (MHP), the state’s primary housing program, disincentivizes building funding for people with IDD. This is contrary to SB 3 (Beall) and must be addressed.

Accessory dwelling units (ADU) are an alternate way to create housing for families with the resources to build them. There are different interpretations of ADU guidelines across regional centers about which ADUs qualify for supportive living services. This should be uniform across the state.

Navigating housing options is complex and confusing. There needs to be a user guide in plain language that explains resources and rights.

Lead on Employment

The federal Workforce and Innovation Opportunity Act has critical definitions for competitive integrated employment. California should adopt these same definitions.

People with IDD should be at least paid minimum wage when they work. The state should stop running sheltered workshops at Department of Developmental Services funded facilities.

The Paid Internship Program is a critical entry into developing skills and impressing future employers while being paid. The sunset that would end the Paid Internship Program should be removed.
**Lead on Safety**

Public Safety Power Shutoffs (PSPS) are here for the foreseeable future. The major utilities must be in regular communication with disability advocates to identify and solve problems PSPS cause.

Disability Justice reports that only 3% of sex abuse involving people with developmental disabilities is ever reported. There are efforts across the country to address these unrecognized and unpunished crimes.

Similarly, people with disabilities are four to ten time more likely to be victims of abuse, neglect, and crime. Everyone deserves to be safe.

The inability to get proper, timely dental care leads to life risking health complications and behaviors. We are ready to join with dentists who are equally frustrated with the barriers to care for useful solutions.

Authorized representation is the best unknown option in family’s toolbox when dealing with difficult decisions. This SCDD authority must be widely known.

While we have solutions ready for this legislative session for housing and employment, solutions for safety will be developed over the next year and beyond. These require coalitions to pinpoint practical solutions that will make a true difference.

**SIDE BY SIDE EXPERTISE**

In addition to driving on the issues above, SCDD will continue its leadership by providing expertise on several policy conversations underway.

**Expertise on Employment**

The Department of Education asked for public feedback on the plan to strengthen Career Technical Education. SCDD advised on ways to improve the plan by including additional focus on people with disabilities.

The Department of Rehabilitation is seeking public input on the Workforce Innovation Opportunity Act State Plan. SCDD is currently reviewing the plan and preparing comments.
The Council sponsored legislation to name SCDD to the Interagency Advisory Committee on Apprenticeships and created a disability workgroup for this committee. The goal is to get 5,000 new people into apprenticeships.

The Governor created a Diversity Task Force to make the State a model employer in many areas, including being a workplace for employees with disabilities. SCDD asked to join this task force.

SCDD continues to support the Employment First Committee, look for opportunities to be more formally involved with the Competitive Integrated Employment Blueprint, as well as seek opportunities for collaboration with the California Committee for the Employment of People with Disabilities.

**Expertise on the Systemwide Efforts for the Developmental Services System**

The DDS Director Nancy Bargmann reestablished the DS Task Force, with the SCDD Chair and Executive Director as members. The Task Force also has five workgroups, and SCDD is represented on each of these workgroups.

The community oversight of the Self Determination Program continues to be a key to seeking the program’s success. SCDD leads in this area by convening the Statewide Self Determination Advisory Committee and having responsibility for surveying participants’ satisfaction and reporting to the Legislature by June 2021.

Implementing the Home and Community Based Services Settings Final Rule by 2022 will be a major focus over the next two years. SCDD is on the DDS workgroup, which has created a timeline for implementation, and remains a partner with vendors who are seeking contracts with the Department to aid in this compliance work.

Many advocates are pushing for funding and implementation of the rate study, which states the service delivery system is underfunded by $1.8 billion. SCDD will continue to be involved with these efforts. Other funding efforts may include restoring recession-era cuts to social, recreation, and camp funding.

The Health and Human Services Agency convenes the Olmstead Committee to ensure the involvement of people with disabilities and other system stakeholders in making recommendations on actions to improve California’s long-term care.
system. SCDD has been represented in the past and is seeking to serve on this committee again.

**Expertise in Other Efforts**

Cal Achieving a Better Life Experience (CalABLE) continues to expand as more individuals with developmental disabilities sign up and accrue assets protected from being counted against receiving public benefits. The Council continues to serve on the CalABLE Board to oversee the program’s implementation.

The Health and Human Services Agency is carrying out the Governor’s Executive Order to create a Master Plan on Aging. The Council will give input on this Plan before it is published in October 2020.

SCDD received a grant from DDS to reduce disparities by working with the Georgetown Center for Cultural Competence and two regional center directors to identify targeted efforts to reduce disparities in those catchment areas. Additionally, SCDD continues to be a member of the Georgetown NCCC Community of Practice with DDS, Disability Rights California, and the University Centers for Excellence in Developmental Disabilities on identifying statewide opportunities to reduce disparities in regional center services.

**CONCLUSION**

These are the proposed targeted policy areas for the Council and HQ for 2020. They are in alignment with the State Plan and in addition to the work happening throughout regional offices. They are ambitious and multi-yeared. With the Council’s support and direct efforts, SCDD can make significant progress in meaningful areas targeted to moving the system forward.
POLICY PLATFORM

ABOUT THE STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Close to fifty years ago, the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) established in federal statute, State Councils on Developmental Disabilities in each of the 56 states and territories to “promote self-determination, independence, productivity, integration, and inclusion in all aspects of community life” for people with intellectual and developmental disabilities (I/DD) and their families through advocacy, capacity building and systems change. The Lanterman Act established the California State Council on Developmental Disabilities (Council) to fulfill those rights.

The Council is comprised of 31 members appointed by the Governor, including individuals with I/DD and their families, and representatives from the DD Act partners (Disability Rights California, the 3 University Centers for Excellence in Developmental Disabilities), and mandated state agencies that provide services and supports to people with I/DD.

To implement the rights in the DD Act, the Council develops and implements a five-year state plan that contains goals, objectives, strategies and outcomes designed to improve and enhance the availability and quality of services and supports. In addition to the Council’s Sacramento headquarters, regional offices support individuals with I/DD and their families through activities such as advocacy, training, monitoring, and disseminating and collecting public information. The Council works with policymakers and other stakeholders to ensure policies pertaining to the rights of individuals with I/DD are protected and enhanced by ensuring people with I/DD can experience equality of opportunity, full participation, independent living, and economic self-sufficiency. These four pillars are enshrined in the Americans with Disabilities Act of 1990 (ADA). The Council supports the full and robust implementation and enhancement of recent federal policies that enshrine the values of the ADA, such as the Workforce Innovation and Opportunities Act (WIOA), Home and Community-Based Services Setting Rule (HCBS), Every Student Succeeds Act (ESSA) and Achieving Better Life Experience (ABLE) Act.
The Council believes that individuals with I/DD and their families must be included and consulted in all aspects of the policy making process to ensure their needs are adequately and appropriately addressed. The Council works to address disparities in access, outcomes, and quality for all services and supports. The Council believes in ensuring transparency and accountability for state and federal programs providing services and supports to people with I/DD. Furthermore, the Council believes that complexities in the service delivery system must be reduced and that assistance in navigating services and supports should be provided to people with I/DD and their families. The State of California must ensure that funding is used to achieve positive outcomes for individuals with I/DD and their families.

Disparities in services and supports can result in severe health, economic, and quality of life consequences. Accordingly, services and supports must be distributed equitably so that individual needs are met in a culturally appropriate and linguistically competent manner, regardless of race, ethnicity, income, intellectual or physical ability, age, and geographic location. Information and materials shall be provided in plain language and/or alternative formats as requested.

**PROMISE OF THE LANTERMAN ACT**

The Lanterman Act promises to honor the needs and choices of individuals with I/DD by establishing an array of quality services throughout the state. Services shall support people to live inclusive lives in their communities. Access to needed services and supports must be inclusive and not be limited to service caps, means testing, median rates, family cost participation fees or other financial barriers. California must not impose artificial limitations, delays or reductions in community-based services and supports that would compromise the health and safety of persons with I/DD.

**SELF-DETERMINATION**

Individuals with I/DD and their families must be given the option to select and direct their service dollars and their services through Self-Determination. The person with I/DD is in charge. With the support of those they choose and trust, people with I/DD and their families are empowered to develop their own unique needs, develop their own life goals, and construct those services and supports most appropriate to reach their full potential. The process begins with a Person Centered Plan (PCP) which details their unique needs, competencies, and aspirations. Self-Determination gives individuals with I/DD the tools and the basic human right to pursue life, liberty and happiness in the ways that they choose.

**SELF-ADVOCACY**

Individuals with I/DD must be in charge of their lives and be respected for the choices made. They must be provided the opportunity and support to be heard and be leaders in the service system and society including voting and other civic responsibilities. Self-advocates must have access to training, assistive technology, information and
materials in plain language and opportunities to participate in the policy making process.

**EMPLOYMENT AND ECONOMIC SELF-SUFFICENCY**

Employment in the community, at least minimum wage or above, is known as competitive integrated employment (CIE). CIE is the priority outcome for working age individuals with I/DD regardless of the severity of their disability. CIE provides every person a chance to build relationships with co-workers, be a part of the community and contribute to the local economies. It reduces poverty and reliance on state support and leads to greater self-sufficiency. Employers must be prepared and supported to employee people with I/DD. The Council supports the full and robust implementation of California’s Employment First Law. Pathways to CIE must be developed and supported for all people with I/DD regardless of severity of disability.

Transition planning should begin as early as possible. Policies and practices must set expectations for integrated employment, microenterprise training, self-employment, and promote collaboration between local agencies, state agencies, and remove barriers to CIE through access to information, benefits counseling, job training, inclusive postsecondary education, and appropriate provider rates that incentivize quality and inclusive employment outcomes. The Council supports the phasing out and elimination of subminimum wage and/or segregated employment for all individuals with I/DD.

**TRANSPORTATION**

Access to transportation is essential to the education, employment, healthcare and inclusion of individuals with disabilities. Timely accommodations must be available to persons with I/DD that are available to the public at-large. Mobility training must be a standard program among transportation providers to increase the use of available transportation and reduce reliance on costlier segregated systems. Barriers between geographic areas and transportation systems must be addressed so people with I/DD can travel as safely and easily as people without disabilities. Emerging transportation options must be available to persons with I/DD.

**HEALTH CARE**

Every person must have access to comprehensive, timely, quality, affordable health care, dental care, and wellness services, and access to plain language information and supports to make informed decisions about their health care. This requires informed consent, individualized, appropriate medication, treatments, and an adequate network of health professionals. It also includes people with multiple health care needs, those who require routine preventative care, mental and/or behavioral health treatment, dental care, durable medical equipment, and reproductive health needs. Service system complexities must not delay, reduce or deny access to services. Individuals must be reimbursed for insurance co-pays, co-insurance, and deductibles when their health insurance covers therapies that are on their Individual Program Plans (IPPs).
EDUCATION

Every student has the right to be safe in school and to receive a quality education with their peers that prepares them for post-secondary education and/or meaningful employment in the community. Schools must ensure robust implementation of the Individuals with Disabilities Education Act (IDEA), Every Student Succeeds Act (ESSA), and other federal and state laws and regulations, to ensure that students with I/DD receive a free appropriate public education (FAPE).

Students with disabilities must be educated alongside their peers without disabilities in the least restrictive environment. Parents must be provided information and training regarding how to access FAPE and Least Restrictive Environment (LRE). Comprehensive transition planning must be considered part of the Individual Education Program (IEP) process. School districts and other educational agencies must be held accountable for implementing the letter and the intent of all state and federal laws. Parents and students must have equal participation in the IEP process, including the ability to give informed consent.

Teachers, school leaders, paraprofessionals and other school-based professionals must be trained to use valid, positive, and proactive practices, such as individualized school-wide positive behavior interventions and supports, with fidelity. The needs of the student must not impact the child’s placement in the least restrictive environment. The Council opposes the use of all forms of seclusion and restraint.

HOUSING

Statewide inclusive living options for individuals with I/DD must be increased and enhanced through access to housing and subsidies that are paired in a timely manner with needed supports and services. Community education and integration must be provided to reduce discrimination. Permanent, affordable, accessible, and sustained housing options must be continually developed to meet both current and future needs.

COMMUNITY PARTICIPATION

Individuals with I/DD must have access to and be fully supported to fully participate in their communities, with their peers without disabilities, through opportunities in all areas of community life including but not limited to education, employment, recreation, organizational affiliations, spiritual development, and civic responsibilities.

TRANSITION TO ADULT LIFE

All services, including education, rehabilitation, independent or supported living and regional center services, must support students and adults to transition to competitive integrated employment, post-secondary education or other opportunities that will lead to meaningful employment in the community. Transition services must be considered at the earliest possible opportunity and across the lifespan. Adults with I/DD must have access to meaningful activities of their choice with the appropriate services and supports including aging adults.
SAFETY

All people have a right to be safe. Every person must be provided emergency preparedness training for all types of emergencies or disasters. Individuals with I/DD experience a much greater rate of victimization and a far lower rate of prosecution for crimes against them. The same level of due process protections must be provided to all people. Individuals with I/DD should be trained in personal safety, how to protect themselves against becoming victims of crime, and how their participation in identification and prosecution can make a difference. In addition, too many interactions between law enforcement and people with I/DD end in avoidable tragedy. Law enforcement personnel, first responders, emergency medical professionals and the judicial system must be trained in how to work with people with I/DD during the course of their duties, including those who are suspects, victims or witnesses of crimes. The Council opposes the use of all forms of seclusion and restraint.

QUALITY AND RATES FOR SERVICES AND SUPPORTS

Having access to and receiving quality services and supports is the cornerstone for people with I/DD to be safe, healthy, and to promote self-determination, interdependence, and inclusion. An adequate safety net must be in place to immediately and timely address medical, mental health, behavioral, residential, staffing, equipment, or other needs when those services or supports fail, are interrupted, are not available, or additional services and supports are necessary for urgent or immediate need.

The state must streamline burdensome and duplicative regulations and processes that do not lead to positive inclusive outcomes for people with I/DD and their families. Quality and timely assessment and oversight must be provided. The state must measure what matters, be administered in a culturally competent manner and the results made public and used to improve the system of services and supports.

The state must restore and provide ongoing monitoring of rates to adequately support the availability of quality services for people with I/DD. A planned and systematic approach to rate adjustments must prioritize and incentivize services and supports.

For more information, contact:
Cindy Smith, Deputy Director for Policy and Public Affairs
cindy.smith@scdd.ca.gov | 916-263-7919
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PROTECTING AND ENHANCING CIVIL RIGHTS

Every person with a developmental disability has the right to self-determination, equality of opportunity, full participation, independent living and economic self-sufficiency regardless of how significantly the person is impacted by their disability.

The Council will work to ensure civil rights are protected and enhanced. The Council will work to ensure the full and robust implementation of recent federal policies that enshrine the values of the Americans with Disabilities Act including the Workforce Innovation and Opportunities Act (WIOA), Home and Community-Based Services (HCBS) Settings Rule, Every Student Succeeds Act (ESSA) and Achieving Better Life Experience (ABLE) Act.

PROMOTING ACCESS TO QUALITY SUPPORTS IN THE COMMUNITY

Every person with a developmental disability should have access to and be fully supported to fully participate in their communities with people without disabilities. Having access to and receiving quality services and supports is the cornerstone for people with developmental disabilities to be safe, healthy and to promote self-determination, interdependence and inclusion. Services and supports in the community require adequate wages for providers. The state must restore and provide ongoing monitoring of rates to adequately support the availability of quality services and supports for people with developmental disabilities. A planned and systematic approach to rate adjustments must prioritize and incentivize quality services. Disparities in access, outcomes, and quality for all services and supports must be addressed. Complexities in the service delivery systems must be reduced. Assistance in navigating services and supports should be provided to individuals with developmental disabilities and their families.

The Council will work to continue to restore the Department of Developmental Services programs cut in 2009. The Council will work to make meaningful improvements to the service delivery system to reduce disparities, increase transparency and accountability and increase quality outcomes. The Council will support efforts to provide adequate wages to providers for inclusive and quality services and supports. The Council will work to ensure successful implementation of the Self-Determination Program.
IMPROVING HOUSING AND COMMUNITY LIVING

Every person with a developmental disability should have the opportunity to live in the community. Permanent, affordable, accessible and sustained housing options must be continually developed to meet both current and future needs. Statewide inclusive living options for individuals with developmental disabilities must be increased and enhanced through access to housing and subsidies that are paired in a timely manner with needed services and supports.

*The Council will work to implement the policy recommendations in the Statewide Strategic Framework for Housing. The Council will work to create a dedicated housing fund to support integrated community housing for people with developmental disabilities.*

GUARANTEEING ACCESS TO COMPETITIVE INTEGRATED EMPLOYMENT

Every person with a developmental disability should have the opportunity to be employed in the community and receive at least minimum wage. Employment in the community, at minimum wage or above, is known as competitive integrated employment (CIE). CIE is the priority outcome for working age individuals with developmental disabilities regardless of the severity of their disability. Pathways to CIE must be developed and supported for all people with developmental disabilities. Transition services must be considered at the earliest possible opportunity and across the lifespan. Policies and practices must promote collaboration and remove barriers to CIE through access to information, benefits counseling, job training, inclusive postsecondary education and appropriate provider rates that incentivize quality and inclusive employment outcomes. The Council supports the phasing out and elimination of subminimum wage and/or segregated employment.

*The Council will work to ensure the full and robust implementation of the Workforce Innovation and Opportunity Act, California’s Employment First Law and the Blueprint for Change. The Council will work to ensure that policies and practices improve opportunities for and incentivize CIE. The Council will work to create incentives and provide supports to all types of employers and contractors for hiring employees with disabilities. The Council will work to make the State of California a model employer.*

ENSURING SAFETY IN THE COMMUNITY

Every person with a developmental disability must be safe. Every person must be provided emergency preparedness training. Law enforcement personnel, first responders, emergency medical professionals and the judicial system must be trained in how to work with people with developmental disabilities (including those who are suspects, victims or witnesses of crimes) during the course of their duties.

*The Council will work to ensure people with developmental disabilities are safe, free from abuse and neglect and have access to services and supports in their communities during all types of disasters or emergencies.*

For more information, contact: Cindy Smith, Deputy Director for Policy and Public Affairs at cindy.smith@scdd.ca.gov | 916-263-7919
As California confronts a historic housing crisis, few are more vulnerable than the 625,000 adults with developmental disabilities. Less than 16% of adults with developmental disabilities have their own home. Over 77% are at risk of losing their housing within this decade.

Micaela Connery, CEO of the The Kelsey, and Aaron Carruthers, SCDD Executive Director will present information about housing in the State of California, how individuals with IDD are affected, and a solution to use one-time surplus funding and existing housing programs.
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State Council on Developmental Disabilities
Statewide Strategic Housing Framework

Expanding Housing Opportunities for People with Intellectual and Developmental Disabilities

Aaron Carruthers
State Council on Developmental Disabilities Meeting
January 28, 2020
People with IDD Need 20,000 New Housing Units

• History of Institutionalization

• Mandate of Inclusion

• Where People Live Now

• Where Do People Want to Live

• Solution
Who is a person with an IDD

• Substantial disability caused by a mental and/or physical impairment
• Starts before age 18 and likely to continue indefinitely
• Or, a condition from birth to 9, that without services is likely to result in a disability later in life
• Functional Impairment in 3 or more areas:
  ▫ Self-Care
  ▫ Communication (receptive and expressive language)
  ▫ Learning, remembering, problem solving
  ▫ Mobility
  ▫ Self-Direction
  ▫ Independent living
  ▫ Economic self-sufficiency
Who is a Person with an IDD

- Includes the following conditions
  - Epilepsy
  - Autism Spectrum
  - Cerebral Palsy
  - Intellectual Disability
  - Other conditions closely related to intellectual disability that require similar supports

- $7.8 billion annually to support people with IDD
- Provided statewide through 21 Regional Centers
  - Private, non-profits that contracted by the Department of Developmental Services to coordinate lifelong services and supports through vendored service providers
  - Alta California Regional Center serves this area and a 10 county area
Who is a Person with an IDD

- 340,000 people served through California's regional centers statewide
- 625,000 Californians according to federal estimates
History of Institutionalization

- 1853 – System of large, public hospitals for the "mentally disadvantaged" began with the establishment of the Insane Asylum of California at Stockton, which later became the Stockton Developmental Center to provide in-patient care and treatment
  - Agnews Developmental Center (closed)
  - Canyon Springs (active)
  - Lanterman Developmental Center (closed)
  - Fairview Developmental Center (to close December 2019)
  - Porterville Developmental Center (active)
  - Sierra Vista Developmental Center (closed)
  - Sonoma Developmental Center (closed)
  - Stockton Developmental Center (closed)

- 1968 – peak of population with 13,400 living in developmental centers
- 2012 – moratorium on new admissions
- 2015 – Governor and Legislature close non-forensic developmental centers
- 2019 – current population of approximately 250
Mandate for Inclusion

• 1969 – Lanterman Act
  ▫ Services and supports in the natural community, home, work and recreational settings

• 1981 – Medicaid Home and Community Based Services (HCBS)
  ▫ Use Medicaid funds to provide a broad array of non-medical services (excluding room and board) not otherwise covered by Medicaid, if those services allow recipients to receive care in community and residential settings as an alternative to institutionalization

• 1999 – SCOTUS Olmstead
  ▫ People with disabilities have the right to live in communities rather than institutions
Mandate for Inclusion

• 2014 HCBS Final Rule Issued, to be implemented by 2022
• To get federal funding for support services for people with IDD, recipients of services must be in settings
  ▪ Setting is selected by the individual from setting options including non-disability specific settings
  ▪ Is integrated and supports access to the greater community
  ▪ Some services can only be received if recipient is living in a private residence owned, leased, or rented by the member and private residences where member pays for part or all of the lease costs
• HCBS funding makes up 40% of $7.8 billion
Where People Live Now

- Only 16% of adults with IDD meet the HCBS Final Rule requirement for living independently
Where People Live Now

- 63% are living in a family home with an aging caregiver (100,000)
- 16% are living independently (26,000)
- 15% are living in a congregate residential facility (25,000)
- 5% are living in a skilled nursing facility (8,000)
- >1% are homeless/transient (450)
- >1% are living in a developmental center (250)

- 20,000 new units needed to house 15% of people in institutionalized settings or at risk of losing their housing over the next 10 years
Where Do People Want to Live

People with IDD said:
• 85% “alone or with roommates” – 2018 State Council Strategic Framework
• 79% “own home or apartment” – 2020 Council on Quality Leadership & The Arc US

Parents/ Family members said:
• 52% “On their own” – 2018 State Council Strategic Framework
• 48% “Own home or apartment” – 2020 Council on Quality Leadership & The Arc US

“I want to live with family”
• People with IDD: 14% (Framework), 10% (Arc)
• Family: 25% (Framework), 13% (Arc)
Solution

• SB 3 – “Investment in existing and successful housing programs to expand the state’s housing stock should benefit California’s homeless and low-income earners, as well as some of the state’s most vulnerable populations, including... people with developmental and physical disabilities”
Solution

- Create a specific funding source for IDD funding
  - One-time
  - General Fund
  - Incorporated into the Multifamily Housing Program
  - Function as gap funding
  - Leveraged with other funding
    - California Tax Credit Allocation Committee (TCAC)
    - Transit Oriented Development (TOD)
    - Infill Infrastructure Grant Program (IGG)
    - Affordable Housing and Sustainable Communities Program (AHSC)
    - Affordable Housing Program (AHP)
    - Community Resources Development Plan (CRDP)
    - Private investment
Solution

Average of $175k gap funding needed per project

- $400 million one-time funding would meet 11% of the need
  - Able to fund 2,285 projects

- $250 million one-time funding would meet 7% of the need
  - Able to fund 1,428 projects

- $100 million one-time funding would meet 3% of the need
  - Able to fund 571 projects
Solution

• Addressing housing needs of adults with disabilities
  ▫ Ensures affordable housing will be accessible to more Californians
  ▫ Allows people to live the promise of inclusion
  ▫ Continue to counter the history of institutionalization
  ▫ Allows CA to continue to draw down federal funding for supports
  ▫ Incorporates people with disabilities as part of a comprehensive solution to the statewide housing crisis
  ▫ Gives families options for the future
Questions?
Recognizing that California’s over-65 population is projected to grow to 8.6 million people by 2030, Governor Gavin Newsom issued an executive order calling for the creation of a Master Plan on Aging to be developed by October 1, 2020. The Master Plan will serve as a blueprint that can be used by state government, local communities, private organizations and philanthropy to build environments that promote an age friendly California. Joseph Rodrigues of the California Department of Aging (DOA) will present Councilmembers with a report on the progress of the Master Plan on Aging. The Council may provide comments to shape the plan.
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California’s Master Plan for Aging
Governor Gavin Newsom Calls for Creation of a Master Plan for Aging

Governor’s Executive Order calls for the Secretary of the Health and Human Services (HHS) Agency to convene a cabinet-level Workgroup for Aging to advise the Secretary in developing and issuing the Master Plan.

The order also directs HHS to convene a Master Plan for Aging Stakeholder Advisory Committee, which will include a Research Subcommittee and a Long-Term Care Subcommittee with an interest in building an age-friendly California.
MPA Deliverables

- State Master Plan
- Local Blueprint
- Data Dashboard of State & Local Data
- Best Practice Toolkit for Local Planning (All by October 2020)
- Recommendations for Long-Term Supports & Services (March 2020)
Master Plan for Aging Vision and Values

**Vision:** California for all across the life span.

**Values:**

- Choices – access, quality, and autonomy
- Equity – eliminating health and social disparities due to age, disability, geography, income, race, ethnicity, immigration status, language, religion/faith, sex, gender identity, sexual orientation, and family status
- Dignity and disruption of age-bias, able-ism, and discrimination
- Inclusion and accessibility for all older adults and people with disabilities
- Innovation and evidence-informed practice
- Partnerships among local, state, and federal governments, philanthropy, and private sectors
Master Plan for Aging Goals

Goal 1: Services & Supports. We will live where we choose as we age and have the help we and our families need to do so.

Goal 2: Livable Communities & Purpose. We will live in and be engaged in communities that are age-friendly, dementia-friendly, and disability-friendly.

Goal 3: Health & Well-being. We will live in communities and have access to services and care that optimize health and quality of life.

Goal 4: Economic Security and Safety. We will have economic security and be safe from abuse, neglect, exploitation, and natural disasters and emergencies throughout our lives.
Governor Newsom issued Executive Order N-16-19 in June 2019 calling for the creation of a Master Plan for Aging (MPA) that can serve as a blueprint for state government, local government, private sector, and philanthropy to promote healthy aging and prepare for coming demographic changes. The executive order states:

- The California Health and Human Services Agency (CHHS) shall convene a Cabinet Workgroup for Aging to develop and issue the MPA by October 1, 2020. The MPA shall include key data indicators, with 10-year targets, to support the implementation of the MPA. The MPA shall include recommendations to better coordinate programs and services to serve older adults, families, and caregivers.

- A Stakeholder Advisory Committee, and two subcommittees — Research and Long-Term Services and Support (LTSS) — also shall be convened by CHHS. The LTSS Subcommittee shall submit a report to the Governor by March 2020.

Plan Framework

Vision: California for all across the life span.

Mission: A person-centered, data-driven, ten-year California Master Plan for Aging by October 1, 2020, including a state plan, local blueprint, data dashboard, and best practice tools.

Values:

- Choices — meaning access, quality, and autonomy
- Equity — addressing cumulative disparities due to age, disability, geography, income, race, ethnicity, immigration status, language, religion, sex, gender identity, sexual orientation, and family status
- Dignity and disruption of age bias, ableism, and discrimination
- Inclusion and accessibility for all older adults and people with disabilities
- Innovation and evidence-informed practice
- Partnerships among local, state, and federal governments, philanthropy, and private sectors.

Goals for All Californians:

1. Services & Supports. We will live where we choose as we age and have the support we and our families need to do so.
2. Liveable Communities & Purpose. We will live in and be engaged in communities that are age-friendly, dementia-friendly, and disability-friendly.
3. Health & Well-being. We will live in communities and have access to services and care that optimize health and quality of life.
4. Economic Security and Safety. We will have economic security and be safe from abuse, neglect, exploitation, natural disasters and emergencies throughout our lives.

*See framework document for objectives and guiding recommendations.

- “Together We Engage” Public Engagement
- Master Plan for Aging Framework & Development
- Collaboration & Coordination
- Legislative Partnership
- Transforming California Department of Aging (CDA)
Together We EngAGE Launches EngageCA.org

https://www.engageca.org/
Join CDA and our partners for an informative and interactive webinar series focusing on issues critical to the developing Master Plan for Aging. Beginning January 2020 through April 2020, Webinar Wednesdays will delve into a single topic each week, including housing, transportation, inclusion, disaster preparedness, retirement security, and much more. Toolkits will be provided to help groups host viewing parties, too.

Visit www.ENGAGEca.org for details.
Equity in Focus
Thank You!

Send questions to EngAG@aging.ca.gov

Learn more about the Master Plan for Aging here*: ENGAGECA.org
JANUARY 28, 2020

AGENDA ITEM 12
INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

*Report on the 2020 Census Count*

The United States Census is conducted every ten years, with the goal of obtaining an accurate and complete count of all people living in the U.S. It is important to participate because the results of the Census can impact how voting districts are set up and how federal funds are spent for programs and services.

Vanessa Cuellar and Kyla Irving from the California Foundation for Independent Living Centers (CFILC) will give a presentation for Councilmembers that explains the background and importance of the Census. They will also offer suggestions on how SCDD can help.
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GET INVOLVED FOR AN ACCURATE, COMPLETE COUNT IN 2020
What do you already know about the Census?
Shape your future
START HERE

United States
Census
2020
Today’s Goals:

- Basics of the Census
- Your role in a successful 2020 Census
- Resources from the #DisabilityCounts2020 Campaign
What is the Census?

The survey asks for the following things:

- Name
- Relationship to people you live with
- Sex (only options are male/female; leave blank if non-applicable)
- Age
- Date of birth
- Race & Hispanic origin
- What housing you live in
Does the census ask about disability?

No.

So, why is it important that I complete it?
Goal of Census

An ACCURATE & COMPLETE count of all people living in the United States.

Every person is counted once.

Every person’s correct information is collected.
When is the Census?
The Census happens every 10 years (the first Census was in 1790!)

When is the 2020 Census?
March - August 2020
Who takes the census?

- ALL people living in the US, those with and without documentation.
- ALL people of all ages - the oldest and the youngest.
**How does the Census actually happen?**

<table>
<thead>
<tr>
<th>Federal Census Bureau</th>
<th>State-by-State</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hires workers and surveys people</td>
<td>• State government leadership and funding</td>
</tr>
<tr>
<td>• Governs the Census</td>
<td>• Participation of local governments</td>
</tr>
<tr>
<td>• Provides help and guidance</td>
<td>• Engagement of nonprofit organizations, businesses, etc.</td>
</tr>
<tr>
<td>• Provides funding/money</td>
<td></td>
</tr>
</tbody>
</table>
How will we get an accurate, complete count?

California Complete Count Committee

County & City Committees

Community Partners
15 Hard-to-Count Populations in California

<table>
<thead>
<tr>
<th>People with disabilities</th>
<th>Older Adults</th>
<th>Middle Eastern &amp; North African</th>
<th>Black/African American communities</th>
<th>Latino communities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Farm workers</td>
<td>Children under 5 years old</td>
<td>Rural communities</td>
<td>Native American &amp; Tribal communities</td>
<td>Renters</td>
</tr>
<tr>
<td>People experiencing homelessness</td>
<td>LGBTQ individuals</td>
<td>Immigrants and Refugees</td>
<td>Limited English Proficiency</td>
<td>Low broadband rates and limited to no access</td>
</tr>
</tbody>
</table>
Where does the Census happen?

- By Mail
- Online
- By Phone
- At a Questionnaire Assistance Center (QAC) near you
- In Person*
Why is the Census important?

- Representation in Congress
- Federal funding for programs and services across the country.
How does the Census impact your community?

- Education
- Food & Housing Support
- Emergency Services & Disaster Response
- Long term Services & Supports
- Employment & Vocational Rehab
- Health Care
- Services for Rural communities
COUNTING FOR CALIFORNIA:

$115,133,486,972
Why is the Census important to people with disabilities?
Continued - Why is the Census important to people with disabilities?

Our services & supports

Fair and accurate government representation

Unequal Barriers
Additional Barriers For People With Disabilities

- Communication and language
- Limited or no access to the internet
- Accessibility of online form and website
- Distrust and fear of the government
- Accessibility of all outreach and education
- Disability cultural competency

And more...
Increasing internet access for people with disabilities
Is information taken by the Census private?
Title 13 of the U.S. Code is designed to keep your information confidential.
**DISCUSSION:**
Inclusion and Reaching a Complete Count

- What barriers may impact your local communities of people with disabilities?
- What will your local regional center do to help?
- Who and what organizations do people trust most?
What can CFILC and DREDF provide?
Statewide Outreach

- Partnership with Disability Community and Older Adult Organizations
- Training
- Marketing Assistance
#DisabilityCounts2020

Contact:

• Kyla Aquino Irving
  kyla@cfilc.org

• Vanessa Cuellar
  vanessa@cfilc.org

DisabilityCounts2020.org
The Speaker of the California State Assembly created a Select Committee on Intellectual and Developmental Disabilities in 2018, chaired by Assemblymember Jim Frazier. In 2019, this Select Committee held eight hearings throughout California to hear from the community about their experiences with regional centers and the service delivery system. The Select Committee also issued a survey. Chair Frazier is holding a meeting of the Select Committee to release the results of the survey. The Council has been called to testify at the Assembly Select Committee hearing on January 28th. Attendees will share their experience with the Councilmembers after attending the hearing.