State Council on Developmental Disabilities Bay Area Office

Community Outreach & Regional Advisory Committee (RAC) Meeting

Wednesday, June 25, 2025 Networking 5:15-5:30 PM Meeting 5:30-8:00 PM This is a hybrid meeting: In-Person with Zoom / Teleconference options.

Members of the public may participate in-person, telephonically, or by Zoom from any location. Accessible formats of all agenda and materials can be found at least 10 days prior to the meeting at: www.scdd.ca.gov/bayarea/.

Join In-Person:

Hosted by San Francisco City Hall, Room 305 1 Carlton B Goodlett Place, San Francisco

Or Join by Zoom:

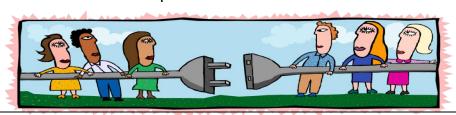
https://us02web.zoom.us/j/89894874557?pwd=b42fX0dQgxxhUbbacqySKQa33a4Bd6.1

Meeting ID: 898 9487 4557 Passcode: 926767

Or by Telephone, U.S. Toll-free: (877) 853-5257 or (888) 475-4499

Collaboration is key! *All are welcome*. Featured: Intergenerational Trauma in Autistic Families workgroup update; State Council's 'There Should Be a Law' Contest; RAC member & Councilmember updates; community partner updates, and more.

This meeting will feature live English captioning. Individuals who require accessible alternative formats of the agenda and/or language interpretation (in Spanish or other languages) and/or auxiliary aids/services to participate in this meeting should contact us at **510-286-0439** or **bayarea@scdd.ca.gov**, at least five business days prior to the meeting. This meeting complies with Government Code Sections 11123.1, 11123.2, and 11125(f). Members may be physically present at one or more teleconference locations. There may be members of the public body who are remotely participating in today's meeting that were granted a reasonable accommodation per the Americans with Disabilities Act.



Concilio Estatal en Discapacidades del Desarrollo Oficina del Área de la Bahía Alcance Comunitario Y

Reunión del Comité Asesor Regional

Miércoles, 25 de junio de 2025 Oportunidad de red 5:15-5:30 PM Reunión 5:30-8:00 PM

Esta es una reunión híbrida: Presencial con opciones de Zoom/Teleconferencia.

El público puede participar en persona, por teléfono o por Zoom desde cualquier lugar. Los formatos accesibles de todos los programas y materiales se pueden encontrar al menos 10 días antes de la reunión en: www.scdd.ca.gov/bayarea/.

Únase en persona:

Organizado por el Ayuntamiento de San Francisco, Habitación 305 1 Carlton B Goodlett Place, San Francisco

Únase por Zoom:

https://us02web.zoom.us/j/89894874557?pwd=b42fX0dQgxxhUbbacqySKQa33a4Bd6.1

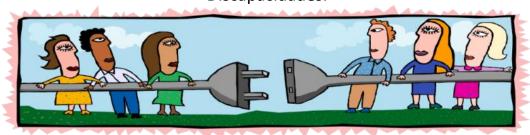
O por teléfono, número gratuito de EE. UU.:

(877) 853-5257 o (888) 475-4499

ID de la reunión: 898 9487 4557 Contraseña: 926767

La colaboración es clave! *Todos son bienvenidos*. Destacado: Actualización del grupo de trabajo sobre el trauma intergeneracional en las familias autistas; Concurso 'Debería haber una ley' del Concilio Estatal; Actualizaciones de los miembros del RAC y del Concilio; actualizaciones de los socios comunitarios, y más.

Esta reunión contará con subtítulos en inglés en vivo. Las personas que requieran formatos alternativos accesibles de la agenda y/o interpretación de idiomas (en español u otros idiomas) y/o ayudas/servicios auxiliares para participar en esta reunión deben comunicarse con nosotros al **510-286-0439** o **bayarea@scdd.ca.gov**, por lo menos cinco días hábiles antes de la reunión. Esta reunión cumple con las Secciones 11123.1, 11123.2 y 11125(f) del Código de Gobierno. Los miembros podrán estar físicamente presentes en una o más teleconferencias. Puede haber miembros del organismo público que están participando remotamente en la reunión de hoy a los que se les ha concedido una acomodación razonable según la Ley de Estadounidenses con Discapacidades.





STATE COUNCIL ON DEVELOPMENTAL DISABILITIES (SCDD)

BAY AREA REGIONAL ADVISORY COMMITTEE (RAC) MEETING & COMMUNITY OUTREACH

NOTICE & AGENDA*

Date Wednesday, June 25, 2025

ne Networking 5:15pm – 5:30p, Meeting 5:30pm – 8:00pm

Locations This is a hybrid meeting: In-Person with Zoom / Teleconference options.

Members of the public may participate telephonically, or by Zoom from any

location. This meeting will feature live captioning, via Zoom.

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5:30p Call to Order
Introductions / Welcomes
Establishment of Quorum

Witkin



5:37p Approval of the April 2025 Meeting Minutes

Witkin



5:40p Public Comment

An invitation to provide the public an opportunity to comment and/or present information to the Committee on **any matter that is not on the agenda**. Each public member has up to 3 minutes to speak. Written requests will be considered first. The Committee will provide a public comment period not to exceed 5 minutes total for all public comments prior to action on any agenda item. Legislative office elected officials or staff may also introduce themselves or provide comment.





5:50p Member Reports

SCDD Bay Area Regional Advisory Committee (RAC) & SCDD Councilmembers

Witkin

Hear updates from RAC members and Councilmembers on their regional and statewide advocacy work, trends / needs in their county, and priorities.



6:15p Community Reports

Witkin

- People First Report
- Regional Center Reports
- County Developmental Disabilities Councils Reports
- Statewide Self-Advocacy Network (SSAN)
- National Council on Disability



6:45p BREAK (5 mins)



6:50p Legislative Office Comments

Witkin

An invitation for legislative offices in attendance to provide brief statements, comments on emerging issues, or updates impacting their constituents from disability communities.





7:00p 5th Annual There Should Be a Law Contest: Open NOW!

Arroyo & Nicholau

Here an overview of the State Council's 5th Annual There Should Be a Law Contest from the SCDD's Chris Arroyo. Then brainstorm areas of need, and outreach ideas on how to get the word out about this contest before the July 18th submission deadline.



7:20p Update from the newest Bay Area RAC Workgroup: Intergenerational Trauma and Undiagnosed Autism

Sellergren

Hear the first update from the most recently formed RAC workgroup. The focus of the project is to examine how unrecognized or unsupported autism in families contributes to intergenerational trauma and how this dynamic relates to long-term patterns of addiction, abuse, neglect, and systemic marginalization. Through one-on-one interviews, focus groups, and online surveys, the working group aims to gather data to identify patterns and unmet needs. The ultimate goal is to generate actionable policy recommendations that improve recognition, prevention, and support for autistic individuals and families impacted by multigenerational trauma.



7:45p Update from Bay Area RAC Workgroup: Health Equity Practice & Policy Strategies

Witkin & Nicholau

Hear a short update from the Health Equity Practice & Policy Strategies RAC workgroup.





7:50p Other Announcements & Agenda Items for Future Meetings

Witkin

An opportunity of members of the community to bring up ideas, needs, issues, and concerns.



8:00p Meeting Adjourned

Witkin

*All times indicated, and the order of business are approximate and subject to change. Any agenda items have the potential to be brought for a vote.



State Council on Developmental Disabilities (SCDD)
Bay Area Regional Advisory Committee (RAC) Meeting
April 30, 2025, Minutes DRAFT

This meeting was hybrid--held in person, and through Zoom (video call or call-in)

Location: Marin County Office of Education, 1111 Las Gallinas Ave, San Rafael, CA 94903

Link: https://us02web.zoom.us/j/89894874557?pwd=b42fX0dQgxxhUbbacqySKQa33a4Bd6.1

Meeting ID: 898 9487 4557 **Passcode:** 926767

Committee Members attending in-person: Terri Carol, Marla Silversmith, and Emily Witkin.

Committee Members attending through Zoom: Kerry Rich, Bird Sellergren, Sana Shooshtari, and Florence Wong.

Council Members attending: Alex Reyes.

SCDD Staff: Sheraden Nicholau, Gabriela Solval, and Valerie Buell.

Accessibility Assistance: Captioner Carilyn, Captioner Savannah

Legislative office representation on Zoom: Katie Reynoso from Congressman John Garamendi's office, Nicholas Hargis from Congressman Sam Liccardo's office, Nicole Cuellar-Nelson from Senator Christopher Cabaldon's office, Leslie Bulbuk from Assemblymember Marc Berman's office, Karishma Khatri from Assemblymember Liz Ortega's Office.

Community Partners attending on Zoom: Eric Zigman, Dr. Rebecca Nanyonjo, Sara Desumala, Siobhan Burgos, Sabreena Sahota, Patrick McKay.

Guests attending on Zoom: Adalia Ortiz, Alisa, Jennifer Walsh, Eric Wilfrid, Eyan Gilder, Frances Biderman, Holly Tabor, Izek Campion, Stephanie Parker.

5:30p Chair Emily Witkin called the meeting to order. Valerie Buell took roll call of RAC members and confirmed a quorum was present.

5:31p Approval of meeting minutes for February 26, 2025:

Moved: Terri Carol Seconded: Bird Sellergren

Roll Call Vote:

Ayes: Terri Carol, Bird Sellergren, Sana Shooshtari, Emily Witkin, Florence Wong Abstain: Kerry Rich, Marla Silversmith



Public Comments: Emily Witkin asked for public comments. Highlights included:

- Nicholas Hargis, field representative for Congressman Sam Liccardo, shared
 - o The proposed \$880 billion cut to the federal budget proposed by Republicans.
 - The commitment of Congressman Liccardo to protect Medicaid.
 - He hosted two press conferences in Santa Clara County to bring awareness to the importance of Medicaid funding.
 - Tracking the impact on Individualized Education Programs (IEPs) and 504 plans due to education funding being shifted to the Department of Health and Human Services.
- Holly Tabor shared that the cuts to AmeriCorps have devastated local organizations, nonprofits, and community organizations that serve people with disabilities.
- Kathia Reynosa from Congressman John Garamendi's office shared recent federal budget cut decisions have resulted in cuts to vital programs and some threaten access to inclusive education and support services. Congressman Garamendi is committed to supporting disability communities and is advocating for the restoration and protection of these critical services.
- Leslie Bulbuk from Assemblymember Marc Berman's office shared she has been doing this work for 21 years now and their office is dedicated to being a resource for this community --even for those not in their district.
- Karishma Khatri, District Director for Assemblymember Liz Ortega shared highlights from their legislative package.
 - Some are around transparency and one of those is about health insurance denials, whether the denial was done by Artificial Intelligence (AI).
 - o Another two bills are addressing wage theft.

Member Reports: RAC Members and Councilmembers reported on their regional and statewide advocacy work and priorities.

One or two highlights include:

Terri Carol:

There are concerns about medication management. Especially when the pharmacy or doctor are prescribing larger pills that must be cut in half instead of pills with the correct dose. This may be hard for a person with disabilities to manage, and could lead to wrong doses and serious health concerns.

· Kerry Rich:

- Introduced himself and his advocacy work.
 - He is a veteran, works for the Palo Alto Veterans Association (VA) hospital.
 - He and his wife started a foundation called Joshua's Gift dedicated to advocacy and supporting families & people living with autism. This is named after their son, Joshua.

Bird Sellergren:



- They run an autism-based organization in San Francisco called Bay Area Autism Collective that provides peer support groups to autistic adults.
- There has been harmful rhetoric around autism being framed as a disease/epidemic with a push to find a cure, even though we know autism is hereditary and genetic. People are concerned about the idea of an autism registry where people are potentially going to be tracked.

Sana Shooshtari:

- She currently works at the Department of Rehabilitation (DOR) and is active in the Child Life community as an aspiring Child Life Professional.
- She is currently part of the Diversity, Equity, and Inclusion (DEI) committee through the Association of Child Life Professionals.

Marla Silversmith:

- She will be presenting at the Supporting Inclusive Practices (SIP) virtual conference next week.
- San Mateo County is doing their first appreciation event on May 14th from 4:30p to
 6:30p at the San Mateo Office of Education.
- The Special Education District Advisory Group held a meeting last week. Students provided babysitting; all volunteer.

Emily Witkin

- She mentioned serving on a panel with Sheraden Nicholau at the Supporting Inclusive Practices (SIP) virtual conference.
- She is hearing the same concerns Bird is, from the autistic community, and how we have a mess of a political situation right now.

• Florence Wong:

- San Mateo County's Aging and Adult Services Dept has changed their name to San Mateo County's Aging and Disability Services.
- The San Mateo County (SMC) Commission on Disabilities recently:
 - Held a panel on Paratransit services.
 - Had the American Red Cross present a hands-only CPR exercise.
 - Had UC Berkeley's Disabilities Studies give a talk about their program.
- o Coming up, the SMC Commission on Disabilities will:
 - Have the American Red Cross presenting at the June meeting.
 - Look into climate change and the capacity to offer cooling centers.
 - Collectively read the book, Demystifying Disability.

Community Reports:

People First Highlights:

- Patrick McKay read the report for Bay Area People First (BAPF):
 - BAPF held their monthly meeting in April with a presentation on Medicaid cuts and a "Share Your Story" workshop. The next meeting will be on Jue 18th from 4:30p to 5:45p.



Regional Center Reports Highlights:

- Eric Zigman gave the report for Golden Gate Regional Center (GGRC):
 - GGRC held two legislative breakfast events; one in Marin on April 11th, where Congressman Jared Huffman gave the keynote, and Assemblymember Damon Connolly also participated and spoke. The second event was in South San Francisco on April 25th. There was a focus on the importance of Early Start and the Lanterman Act.
 - The Master Plan on Developmental Services is posted, and the final report pivoted to a greater focus on listening to persons served.
 - GGRC does an unmet needs survey and uses the data from the survey to be able to ask the Department of Developmental Services (DDS) for funding to start new services or expand existing services.
 - Former RAC Chair, Elizabeth Grigsby, was given a Statewide Advocacy Award from Cal-TASH.
- Dr. Becky Nanyonjo gave the report for Regional Center of the East Bay (RCEB):
 - RCEB has been actively involved with legislation, provided testimony on Assembly Bill 1172, about anti-seizure medication and the ability to administer that medication in homes as well as day programs. RCEB's Clinical Director, Lucy Rivello, provided testimony at both sessions.
 - She and her team are seeking to stabilize caseloads, as they have been growing again. RCEB has been involved in the development and conversations around the Workforce Development Bill.
 - DDS Director, Pete Cervinka, spoke during the Senate Budget Sub-Committee session and reemphasized the need to protect the requirements of the Lanterman Act and make sure we fulfill those entitlements.
 - The RCEB Board Meeting was last Monday. Five individuals on the board are terming out. If anyone is interested in being a board member, reach out to her.
 - RCEB was able to contribute to the development of 11 or 12 units from a 75-unit project for independent living in Castro Valley. The groundbreaking ceremony will be on May 9th.

Developmental Disabilities (DD) Councils Report Highlights:

- Gabriela Solval read the report from Vi Ibarra for the Contra Costa County Developmental Disabilities Council.
 - May 5th is the last day to make nominations for the Developmental Disabilities (DD) Council annual awards event. The presentation will be in the afternoon of June 5th at the Shannon Community Center in Dublin.
 - May 17th from 8:30a to 2:00p is the Special Connections Summit in San Pablo.
 This is a free conference and resource fair for families of children aged 3-18 with developmental disabilities. Registration is required.



- There are resources available for the deaf and hard of hearing community including Home Fire Alert devices available from the American Red Cross.
- The next DD Council meeting will be May 28th at Las Trampas with a Zoom option available. The presentation at that meeting will be a review of the Master Plan for Developmental Services.
- Sabreena Sahota gave the report for the Alameda County Developmental Disabilities Council (ACDDC).
 - Sabreena Sahota is the new coordinator with the council and has served Alameda County for about a decade. She worked in healthcare and nonprofits, especially those serving individuals with developmental disabilities.

Statewide Self Advocacy Network (SSAN):

- Sara Desumala read the report:
 - The last SSAN meeting was on March 6th on Zoom. There were presentations on leadership and advocacy, emergency preparation, and "Intro to the Hand in Hand Network". They also had SCDD updates and reviewed the Association of Universities Centers on Disabilities (AUCD) conference. The next meeting is on June 11th & 12th.

National Council on Disability:

- Sheraden Nicholau read the report from Sascha Bittner:
 - The upcoming meetings will be on May 29th and May 30th. The physical meeting will be in New York City and there will be Zoom/call-in information.
 - They will have a policy update and discussion of fiscal year 2026 policy work proposals and priorities, a regional perspective presentation on employment initiatives and challenges for employment of youth with disabilities, another presentation on regional perspectives about youth and younger adults in nursing homes and homestead implementation across the states, and a public comment on youth and younger adults in nursing homes.
 - Members of the council will also have a talkback with the cast from Wicked, about disabled actors on Broadway.

6:40p Six-minute break (resumed at 6:46)

Legislative Office Comment after reports:

- Nicole Cuellar-Nelson from Senate District 3, Senator Christopher Cabaldon's office appreciates the updates everyone is sharing and welcomes those in District 3 to reach out if they need assistance.
- Valerie Buell read a report from Katie Jacobs from Congressman Josh Harder's Office.



- Congressman Harder sent a letter to the U.S. Department of Justice (DOJ) urging the Attorney General to take action against corporate landlords using rent-setting software to artificially inflate prices and called for stronger anti-collusion enforcement to protect renters from price gouging.
- Congressman Harder participated in a roundtable hosted by San Joaquin County Office of Emergency Services alongside Assemblywoman Rhodesia Ransom, County Chair Paul Canepa, and other local, state, and federal leaders. The discussion focused on improving emergency response efforts in the Valley, especially considering recent natural disasters like megafires, droughts, and flooding.
- He emphasized the importance of strong coordination across all levels of government to keep vulnerable communities, including people with disabilities, safe during emergencies.
- Alisa Rosillo, family advocate and community leader shared:
 - She joined Congressman Mark DeSaulnier's Office in Washington DC this spring, representing the IDD and cross-disabilities community at the State of the Union and to speak out against the cuts to Medicaid that are being proposed.
 - She was also able to do three different TV and radio interviews on that subject, as well as doing an informal sit down that Congressman DeSaulnier posted and sent out to his constituents, speaking more to the fact that these cuts are dangerous to the community.

Health Equity Practice & Policy Presentation

- Sheraden introduced Izek Campion from Sutter Health, and Holly Tabor from Stanford University to present on Health Equity Practice & Policy. Some highlights were:
- Izek Campion shared:
 - He is the civil rights compliance manager for Sutter Health.
 - Sutter Health has been incorporating sensory-friendly clinics into their campuses.
 That work started during the pandemic when patients weren't able to access the COVID vaccine.
 - One mobile clinic was built at the BART station in Fremont so people could make an appointment to come there. In Los Gatos, a drive through was set up so patients didn't have to get out of their cars.
 - There are currently three different sites embedded with pediatrics and plans to move into the emergency department.
 - Staff is trained, before the clinic opens, in working with patients who need sensory-friendly clinics.
 - Video Social Stories and other supports and access tools are available to support the patient through the entire process, and patients are invited to do a trial run at a clinic to get more familiar with it.



- There is a multidisciplinary team including a therapist for needle-phobic patients, so they can see the therapist before their appointment.
- In 2022, of 224 participants, 70% rated the experience at a 9 or 10 (with 10 being the best experience). 80% of caregivers rated 9 or 10. 90% would recommend the clinics.
- There are plans to start doing this in the East Bay. There are plans to expand this
 to adults. Adults are being seen already, but it will be more official in the future.
- There is a referral process. As long as Sutter takes the insurance, they can take a referral outside Sutter.

Holly Tabor shared:

- o Holly has a PhD in Epidemiology.
- Stanford serves as a convener in the disability and disability support communities, connecting different organizations working in the community with individuals/families.
- 'Intellectual Developmental Disability (IDD) at Stanford' is a website, an in-person quarterly brunch, and an email list serve, to connect people with IDD, caregivers and family members, community organizations, and Stanford staff/faculty and students about IDD.
- Data from the Cender for Disease Control (CDC) shows one in three adults with disabilities ages 18 to 44 don't have a usual healthcare provider. One in three have unmet healthcare needs because of cost and one in four did not have a routine checkup in the last year.
- She shared stats that speak to attitudinal barriers that patients experience, and the disparity experienced by patients with disabilities. Especially people with disabilities who are also people of color.
- The Autistic Self-Advocacy Network and other organizations made plain language and visual summaries about things like vaccines.
- IDD-TRANSFORM Mission is involved in community based participatory research (CBPR) engaging with adults with IDD in four pressing topics in health care using patient-centered outcomes research methodologies.
 - They have done projects to look at clinics and think about how to make clinic spaces more accessible and are working on a brochure about people with Down syndrome and Alzheimer's disease that people can share with their doctors about how to get screened.

Proposal for a Bay Area RAC Workgroup

 Bird Sellergren proposed the formation of a working group for the RAC to collect data on undiagnosed autism and intergenerational trauma within families to identify contributing factors and specific risks, and to make recommendations to support the community members impacted.



• They reviewed family dynamics, gaps in policy, the impact of failing to diagnose, including those experiencing addiction, neglect, abuse, and incarceration, and the workgroup goals.

7:50p Proposal: Form a RAC working group to policy intervention aimed at policy recommendations to get people the help they need, to stop intergenerational trauma in autistic families.

Moved: Marla Silversmith Seconded: Terri Carol

Roll Call Vote: All Ayes

Other Announcements (highlights):

None

7:54p Meeting Adjourned.



5th Annual There Should Be a Law Contest

If you ever had a problem and thought, "there should be a law to fix this!" Well, there is a solution—**YOU!**

Send the problem and your solution to the California State Council on Developmental Disabilities (SCDD) for a chance for your idea to be selected and become SCDD's next legislative priority!

Q: What ideas can I submit for the contest?

A: The idea must benefit people with intellectual and developmental disabilities.

Q: Who can enter the contest?
A: Anyone can enter the contest.

HOW TO ENTER

Submit your idea online at:

https://bit.ly/BillIdeas2025

Deadline: July 18, 2025





5th Annual There Should Be a Law Contest

Have you ever had a problem and thought there should be a law to fix it? Here is your chance to create the change you want to see.

Enter the California State Council on Developmental Disabilities (SCDD) 5th Annual There Should Be a Law Contest! Anyone can enter! Send your problem and solution for consideration as future legislation sponsored by SCDD.

Past winning ideas include:

- Strengthen plain language used by governmental agencies
- More mental health supports
- Conservatorship Reform: Signed into law https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_i d=202120220AB1663.
- Make Fair Hearings Fair: passed via Budget (AB188/SB188)
 https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=202120220AB188&search_keywords=fair%23%23%23hearings%23%23%23developmental.

The contest will run from June 2 – July 18, 2025. The idea must benefit people with intellectual and developmental disabilities. Please submit your idea here:

https://bit.ly/BillIdeas2025. We will contact the winner when an idea has been selected.

Please email Policy@scdd.ca.gov with any questions.

5° Concurso anual ¡Debería haber una ley!

Si alguna vez tuvo un problema en su vida diaria y pensó, "¡Debería haber una ley para solucionar esto!" Bueno, hay una solución—¡ÚSTED!

Envía el problema y tu solución al Consejo Estatal de Discapacidades del Desarrollo de California (SCDD) para tener la oportunidad de que tu idea sea seleccionada y se convierta en la próxima prioridad legislativa del SCDD.

P: ¿Qué ideas y soluciones puedo presentar para el concurso?

R: La idea y la solución deben beneficiar a personas con discapacidades intelectuales y del desarrollo.

P: ¿Quien puede someter ideas al concurso?

R: Cualquier persona puede participar en el concurso.

CÓMO PARTICIPAR

Envié la idea por la red a:

https://bit.ly/BillIdeas2025

Fecha límite: 18 de julio de 2025





5º Concurso anual ¡Debería haber una ley!

¿Alguna vez has tenido un problema y has pensado que debería existir una ley para solucionarlo? Esta es tu oportunidad de crear el cambio que deseas ver.

¡Participa en el 5º Concurso Anual "Debería haber una Ley" del Concilio Estatal de Discapacidades del Desarrollo de California (SCDD, por sus siglas en inglés)! ¡Todos pueden participar! Envía tu problema y tu propuesta de solución para que sea considerada como una posible legislación futura patrocinada por el SCDD.

Algunas ideas ganadoras de años anteriores incluyen:

- Fortalecer el lenguaje sencillo utilizado por las agencias gubernamentales.
- Ampliar los apoyos de salud mental
- Reforma de la tutela/conservatoria: Convertido en ley: https://leginfo.legislature.ca.gov/faces/billNavClient.xhtml?bill_i d=202120220AB1663
- Hacer que las Audiencias Justas sean realmente justas:
 Aprobado vía presupuesto (AB188/SB188):
 https://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=202120220AB188&search_keywords=fair%23%23%23hearings%23%23%23developmental

El concurso se llevará a cabo del 2 de junio al 18 de julio de 2025 y la propuesta debe beneficiar a personas con discapacidades intelectuales y del desarrollo. Envía tu idea aquí: https://bit.ly/BillIdeas2025. Nos pondremos en contacto con el ganador una vez seleccionada su idea.

Si tiene preguntas, envíe un correo electrónico a Policy@scdd.ca.gov.

Bay Area Regional Advisory Committee (RAC) Working Group Project Overview Intergenerational Trauma and Undiagnosed Autism

RAC Workgroup Members:

Bird Sellergren (workgroup lead), Kerry Rich, Emily Witkin

Sample Composition

This research study is being conducted as part of a working group within the Bay Area Regional Advisory Committee (RAC) of the State Council on Developmental Disabilities (SCDD). The focus of the project is to examine how unrecognized or unsupported autism in families contributes to intergenerational trauma and how this dynamic relates to long-term patterns of addiction, abuse, neglect, and systemic marginalization. The work is grounded in the understanding that autism has historically gone undiagnosed in many families due to structural barriers related to race, class, gender, and geography. As a result, older generations often lacked access to the language, support systems, or frameworks necessary to understand complex behaviors, struggles with emotional regulation, or relational disruptions. These conditions have, in many cases, led to persistent cycles of trauma and systemic exclusion.

Participants include autistic adults who have experienced family systems shaped by unrecognized neurodivergence. Some may hold formal diagnoses, others may self-identify, and others may only recognize traits in themselves or relatives through reflection. Through one-on-one interviews, focus groups, and online surveys, the working group is gathering data to identify patterns and unmet needs. The ultimate goal is to generate actionable policy recommendations that improve recognition, prevention, and support for autistic individuals and families impacted by multigenerational trauma.

Primary inclusion criterion:

- Autistic adults (18+) who have experienced intergenerational trauma in families where autism was historically undiagnosed, unrecognized, or unsupported
 - Participants may have formal diagnoses, self-identify as autistic, or only recognize traits in hindsight
 - We also welcome participants who suspect that autism was present in prior generations (e.g., in parents, grandparents, or siblings) but never named or supported

This study is rooted in the understanding that diagnostic access has historically been limited by race, class, gender, and geography, and that the absence of recognition in earlier generations often resulted in untreated trauma, substance use, or patterns of abuse. Participants do not need to have known they were autistic at the time of their experiences, nor do their family members need to have formal diagnoses. The emphasis is on recognizing the relational impact of missed or delayed understanding of autism over time.

Recruitment Strategy

Community-based sources:

To ensure a diverse and representative sample, recruitment will prioritize community-based organizations that already serve autistic individuals, trauma survivors, and structurally excluded populations. Outreach will focus on building direct relationships with staff, peer advocates, and program coordinators at the following types of sites:

- Disability justice and autism advocacy organizations, with priority given to autistic-led groups that serve adults
- Peer support networks that center trauma recovery, dual-diagnosis experiences, or neurodivergent community building

- Veteran support services and culturally affirming mental health organizations that are familiar with non-traditional communication styles
- Recovery communities, harm reduction spaces, and substance use treatment providers that work with trauma-exposed populations
- Independent Living Centers, mutual aid collectives, and service organizations that assist with housing, reentry, or crisis navigation

Initial outreach will include personalized emails and informational flyers that outline the project's goals and options for participation. Members of the working group could be made available to attend meetings, virtual gatherings, or staff briefings to provide in-person explanations of the project. Referrals from trusted staff members or peer leaders will be prioritized to reduce gatekeeping and build trust.

Accessibility Considerations for Study Design and Implementation

1. Recruitment

- Plain language framing in all outreach materials, avoiding clinical or institutional jargon.
- Multiple formats for recruitment: flyers, text-based emails, audio recordings, and captioned video messages, to meet varied processing and communication needs.
- Community vetting of language through peer review by people with intellectual and developmental disabilities before public release.
- Affirmative framing that centers recognition of experience over diagnostic status, to avoid gatekeeping and accommodate selfidentifying or questioning individuals.

2. Informed Consent

• Layered consent documents that allow participants to engage at different levels of detail (e.g., a short plain-language summary with optional deeper sections).

- Multiple modes for giving consent are available, including written, verbal (recorded), typed, or symbol-supported, depending on the participant's needs.
- Ongoing consent model where participants can revisit or revise their consent preferences throughout the study.

3. Participation Formats

- Online survey, self-paced.
- Flexible modalities for interviews and focus groups: video, phone, chat, asynchronous voice memo, written response, or mixed methods.
- Sensory and emotional pacing support, such as check-ins, content warnings, and the option to take breaks or pause and resume participation at a later time.
- No required real-time interaction; participants can contribute at their own pace or across different times.

4. Communication and Language Access

- AAC-compatible formats and willingness to communicate through typing, spelling boards, apps, or symbol-based systems.
- Interpreter availability (including ASL or language-specific interpreters) is available upon request.
- Pre-shared questions for interviews and focus groups, allowing participants to prepare responses in advance or submit them asynchronously.

5. Privacy and Safety

 Participant-chosen pseudonyms and options for non-disclosure of location, especially for those in recovery or with histories of incarceration. Anonymized data practices that center dignity rather than compliance with academic norms.

6. Spanish Language Access

- All core materials, including recruitment content, consent forms, and surveys, will be translated into Spanish by native speakers with experience in disability and trauma-related contexts.
- Live interpretation will be offered for interviews and focus groups upon request, utilizing qualified interpreters who are familiar with neurodivergent communication.
- Translations will prioritize plain-language clarity and cultural relevance rather than direct literal equivalence.
- Additional language needs will be assessed on a case-by-case basis, and efforts will be made to expand access beyond English and Spanish where possible.

Collaborative Access Oversight

Sheraden Nicholau, as a State Council Regional Manager and experienced access facilitator, will support the design and implementation of accessibility protocols throughout the study. Her role will include:

- Reviewing all public-facing materials for plain-language compliance and cultural access
- Advising on participant outreach methods to ensure reach into multiply-marginalized communities
- Supporting individualized access planning for participants who request accommodations beyond standard formats



The State Council on Developmental Disabilities' (SCDD) Bay Area Regional Advisory Committee (RAC) is taking *applications for membership*!

RACs represent the communities they represent, including geographically and ethnically. The Bay Area RAC is especially interested in meeting: **Applicants from Marin County, identifying as a male or nonbinary; and /or identifying as a self-advocate; and/or identifying as Latino/a or Hispanic, Black, or African American.**

Thank you for your continued efforts in being a voice for the community!

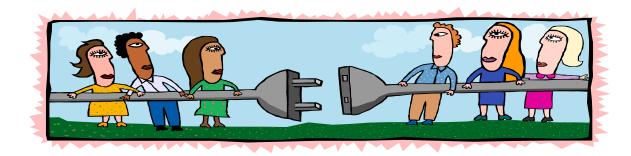
Appointed RAC members:

- Advise SCDD and its Regional Office on local issues in Marin, San Francisco, San Mateo, Alameda, and Contras Costa counties.
- Identify and provide input regarding local systemic needs within its communities.
- Provide public information programs /events for people with intellectual and developmental disabilities, families, professional groups, and the general public to increase awareness of areas identified in the SCDD state plan; and more!

To apply online:

https://docs.google.com/forms/d/e/1FAIpQLSepqt80u578ELHgcPJNzsjO71PPvxZ1txZn77P5Cm 6iVbvBzg/viewform?c=0&w=1

Contact us for more information: bayarea@scdd.ca.gov or call 510.286.0439





State Council on Developmental Disabilities



• website • www.scdd.ca.gov

• email • bayarea@scdd.ca.gov

1515 Clay Street, Suite 803 Oakland, CA 94612 (510) 286-0439

2025-2026 Schedule of State Council Bay Area Regional Advisory Committee (RAC) Meetings (Hybrid meetings)

Members of the public are welcomed and encouraged to participate in these Bay Area Regional Advisory Committee (RAC) meetings, in-person or over teleconference.

These meetings comply with Government Code Sections 11123.1, 11123.2, and 11125(f). Specific meeting details and accessible formats of all agenda and materials can be found at least 10 days prior to the meeting at: www.scdd.ca.gov/bayarea/. There may be members of the public body who are participating in the meeting that were granted a reasonable accommodation per the Americans with Disabilities Act (ADA). Members may be physically present at one or more teleconference locations.

Individuals with disabilities who require accessible alternative formats of the agenda and related materials and/or auxiliary aids/services to participate in any meeting should contact us at bayarea@scdd.ca.gov or call us at **510.286.0439**, a least five (5) business days before that meeting.

Those with other accessibility requests, including language interpretation and/or ASL interpretation, should contact us at bayarea@scdd.ca.gov or call us at 510.286.0439, a least five (5) business days before that meeting.

Networking from 5:15 PM to 5:30 PM, RAC Meeting from 5:30 PM to 8:00 PM.

September 24, 2025: Hybrid meeting, in-person location in Alameda County

December 03, 2025: Hybrid meeting, in-person location in Contra Costa County

February 25, 2026: Hybrid meeting, in-person location in San Mateo County

April 29, 2026: Hybrid meeting, in-person location in Marin County

June 24, 2026: Hybrid meeting, in-person location in San Francisco



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Calendario 2025-2026 del Concilio Estatal Reuniones del Comité Asesor Regional (RAC) del Área de la Bahía

Se da la bienvenida y se alienta a los miembros del público a participar en estas reuniones del Comité Asesor Regional (RAC) del Area de la Bahía.

Estas reuniones cumplen con las secciones 11123.1, 11123.2 y 11123.2 del Código del Gobierno, así como con las secciones 11123.1, 11123.2 y 11125(f). Los detalles específicos de la reunión y los formatos accesibles de todos los temas y materiales se pueden encontrar al menos 10 días antes de la reunión en:

www.scdd.ca.gov/bayarea/. Puede haber miembros del público que estén participando en la reunión a los que se les haya concedido una acomodación razonable según la Ley de Estadounidenses con Discapacidades (ADA). Los miembros pueden estar físicamente presentes en una o más teleconferencias.

Las personas con discapacidad que necesiten formatos alternativos accesibles del programa y los materiales relacionados y/o ayudas auxiliares/servicios para participar en cualquier reunión deben comunicarse con nosotros a través de bayarea@scdd.ca.gov o llámenos al 510.286.0439 al menos cinco (5) días hábiles antes de esa reunión.

Aquellos que tengan otras solicitudes de accesibilidad, incluyendo interpretación en idiomas y/o ASL, deben contactarnos a <u>bayarea@scdd.ca.gov</u> o llamarnos al 510.286.0439, por lo menos cinco (5) días hábiles antes de esa reunión.

Oportunidad de red 5:15 PM a 5:30 PM, Reunión de 5:30 PM a 8:00 PM.

24/9/2025 Reunión híbrida, ubicación en persona en el condado de Alameda
3/12/2025 Reunión híbrida, ubicación en persona en el condado de Contra Costa
25/2/2026 Reunión híbrida, ubicación en persona en el condado de San Mateo
29/4/2026 Reunión híbrida, ubicación en persona en el condado de Marin
24/6/2026 Reunión híbrida, ubicación en persona en el condado de San Francisco