State Council on Developmental Disabilities Bay Area Office Community Outreach & Regional Advisory Committee (RAC) Meeting

Wednesday, April 24, 2024 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: <u>www.scdd.ca.gov/bayarea/</u>.

Join In-Person:

Hosted by the Alameda County Developmental Disabilities Council, Public Health Dept. Creekside Plaza @ 1100 San Leandro Blvd., San Leandro, CA 94577 Oak Conference Room

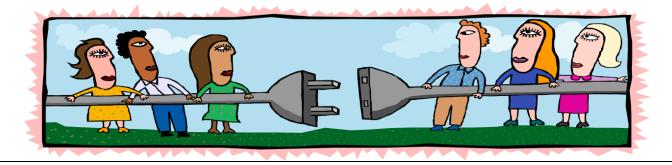
Join by Zoom:

https://us02web.zoom.us/j/82478532905?pwd=Qm9xbVVTMWttRFg1Wm9Ua3dMRkdZUT09 Or by Telephone, U.S. Toll-free: (877) 853-5257 or (888) 475-4499 Meeting ID: 824 7853 2905 Passcode: 559222

Collaboration is key! We invite members of the community to share input, issues and concerns. *All are welcome*. Featured this meeting: Health and healthcare equity work, RAC member updates, community partner updates, and more.

This meeting will feature live captioning and Spanish-language interpretation.

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. Individuals with disabilities who require accessible alternative formats of the agenda and related materials 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.



Concilio Estatal en Discapacidades del Desarrollo Oficina del Área de la Bahía

Alcance Comunitario Y Reunión del Comité Asesor Regional

Miércoles, 24 de abril de 2024 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: <u>www.scdd.ca.gov/bayarea/</u>.

Únase en persona:

Organizado por el Concilio de Discapacidades del Desarrollo del Condado de Alameda, Departamento de Salud Pública.

Creekside Plaza - 1100 San Leandro Blvd., San Leandro, CA 94577, Oak Conference Room

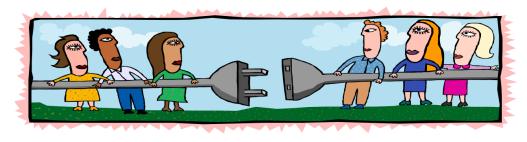
Únase por Zoom:

https://us02web.zoom.us/j/82478532905?pwd=Qm9xbVVTMWttRFg1Wm9Ua3dMRkdZUT09 O por teléfono, número gratuito de EE. UU.: (877) 853-5257 o (888) 475-4499 ID de la reunión: 824 7853 2905 Contraseña: 559222

¡La colaboración es clave! Invitamos a los miembros de la comunidad a compartir aportes, cuestiones y preocupaciones. *Todos son bienvenidos*. Destacado en esta reunión: Trabajo de equidad en salud y salud, actualizaciones de miembros de RAC, actualizaciones de socios comunitarios y más.

Esta reunión tendrá subtítulos en vivo e interpretación en español.

Esta reunión cumple con las Secciones 11123.1, 11123.2 y 11125(f) del Código de Gobierno. Los miembros pueden estar físicamente presentes en uno o más lugares de teleconferencia. Es posible que haya miembros del público que participen de forma remota en la reunión de hoy a quienes se les concedió una adaptación razonable según la Ley de Estadounidenses con Discapacidades. Las personas con discapacidades que requieran formatos alternativos accesibles de la agenda y materiales relacionados y/o ayudas/servicios auxiliares para participar en esta reunión deben contactarnos al (510) 286-0439 o <u>bayarea@scdd.ca.gov</u>, al menos cinco días hábiles antes de la reunión.





STATE COUNCIL ON DEVELOPMENTAL DISABILITIES (SCDD) BAY AREA REGIONAL ADVISORY COMMITTEE (RAC) MEETING & COMMUNITY OUTREACH NOTICE & AGENDA*

Dat

Wednesday, April 24, 2024

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 and Spanish-language interpretation, via Zoom.

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For more information, contact the State Council on Developmental Disabilities Bay Area Regional Office, 510-286-0439 or <u>bayarea@scdd.ca.gov</u>.



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



5:37p Approval of the Jan 2024 & Feb 2024 Meeting Minutes Grigsby



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 A Panel Discussion on Health & Healthcare Equity Work



in the Bay Area Nicholau



What kind of work is being done to reduce disparities people with IDD and other disabilities experience in health and healthcare access? What can advocates and allies do to improve health equity and access in the Bay Area? Hear from a panel of health and healthcare providers, policy professionals, and advocates-- including panelists from the WITH Foundation, University of the Pacific, Arthur A. Dugoni School of Dentistry, and the Stanford Center for Biomedical Ethics. Learn about some of the important work happening in your region, and beyond. Hear examples of what we can do to improve equity and access for our community.



6:50p Additional Legislative Office Comments

Grigsby

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



6:55p Community Reports

Grigsby

- People First Report
- Regional Center Reports
- County Developmental Disabilities Councils Reports
- National Council on Disability





7:20p Member Reports: SCDD Bay Area Regional Advisory Committee (RAC) & SCDD Councilmembers Grigsby

Hear updates from RAC members and Councilmembers on their regional and statewide advocacy work, and their priorities.



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

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



8:00p Meeting Adjourned

Grigsby

*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.



CONCILIO ESTATAL EN DISCAPACIDADES DEL DESARROLLO (SCDD) REUNIÓN DEL COMITÉ ASESOR REGIONAL (RAC) DEL ÁREA DE LA BAHÍA Y ALCANCE NOTICIAS Y AGENDA*

Fech

Miércoles, 24 de abril, 2024

Oportunidad de red 5:15pm – 5:30p, Reunión 5:30pm – 8:00pm

Ubicación Esta es una reunión híbrida: Presencial con opciones de Zoom/Opciones de teleconferencia. El público podrá participar telefónicamente o por Zoom desde cualquier lugar.

Esta reunión contará con subtítulos en vivo e interpretación en español, a través de Zoom.

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Únase en persona:

Concilio de Discapacidades del Desarollo del Condado de Alameda, Sala de Conferencia Oak, 1100 San Leandro Blvd., San Leandro, CA 94577

Únase por Zoom:

https://us02web.zoom.us/j/82478532905?pwd=Qm9xbVVTMWttRFg1Wm9Ua3dMRkdZUT09



O por teléfono, número gratuito de EE. UU.: (877) 853-5257 o (888) 475-4499 ID de la reunión: 824 7853 2905 Contraseña: 559222

Para obtener más información, comuníquese con la Oficina Regional del Área de la Bahía del Concilio Estatal en Discapacidades del Desarrollo, 510-286-0439 o <u>bayarea@scdd.ca.gov</u>.



5:30p Comienza la Reunión Presentaciones/Bienvenidas Establecimiento de Quórum

Grigsby



5:37p Aprobación de las Actas de la Reunión de Enero de 2024 y Febrero de 2024

Grigsby



5:40p Comentario Publico

Una invitación para brindar al público la oportunidad de comentar y/o presentar información al Comité sobre **cualquier asunto que no esté en la agenda**. Cada miembro del público tendrá 3 minutos para hablar. Las solicitudes por escrito se considerarán primero. El Comité proporcionará un período de comentario público que no exceda los 5 minutos en total para todos los comentarios públicos antes de la acción sobre cualquier punto de la agenda. Los funcionarios electos o el personal de la oficina legislativa también pueden presentarse o hacer comentarios.



5:50p Un Panel de Discusión Sobre el Trabajo de Equidad en Salud y Salud en el Área de la Bahía Nicholau



¿Qué tipo de trabajo se está haciendo para reducir las disparidades que las personas con IDD y otras discapacidades experimentan mediante salud y acceso a la atención médica? ¿Qué pueden hacer los auto defensores y aliados para mejorar la equidad y el acceso a la salud en el Área de la Bahía? Escuche a un panel de proveedores de salud y atención médica, profesionales de políticas y defensores-- incluyendo panelistas de la Fundación WITH, la Universidad del Pacífico, la Escuela de Odontología Arthur A. Dugoni y el Centro de Ética Biomédica de Stanford. Conozca algunos de los trabajos importantes que están sucediendo en su región y más. Escuche ejemplos de lo que podemos hacer para mejorar la equidad y el acceso para nuestra comunidad.



6:50p Comentarios Adicionales de las Oficinas Legislativas Grigsby

Una invitación para que las oficinas legislativas presentes proporcionen declaraciones breves, comentarios sobre temas emergentes o actualizaciones que impactan a sus electores de la comunidad de discapacidades.



6:55p Informes de la Comunidad

Grigsby

- Informes de "Gente Primero"
- Informes del Centro Regional
- Informes de los Concilios de Discapacidades del Desarrollo de los Condados
- Concilio Nacional en Discapacidad



7:20p Informes de Miembros: Comité Asesor Regional (RAC) del Area de la Bahía y miembros del Concilio Estatal en Discapacidades del Desarrollo (SCDD) Grigsby



Escuche las actualizaciones de los miembros del RAC y los miembros del Concilio sobre su trabajo regional y estatal, y sus prioridades.



7:50p Otros Anuncios Y Elementos de la Agenda Para Futuras Reuniones Grigsby

Una oportunidad para que los miembros de la comunidad aporten ideas, necesidades, problemas e inquietudes.



8:00p Fin de Reunión

Grigsby

* Todos los horarios indicados y el orden del día son aproximados y están sujetos a cambios. Cualquier punto de la agenda tiene el potencial de ser sometido a votación.



State Council on Developmental Disabilities (SCDD) Bay Area Regional Advisory Committee (RAC) Meeting January 11, 2024, Minutes DRAFT

This meeting was hybrid: Held in-person, and through Zoom (video call or call-in)Location: 1515 Clay Street, Room 10, Oakland, CA 94612Link: https://us02web.zoom.us/j/81386088903?pwd=eHo4RzMwTlhjS2QvbjV4NEZ1bjFqUT09Meeting ID: 813 8608 8903Passcode: 255658

Committee Members Attending in-person: Elizabeth Grigsby and Marla Silversmith

Committee Members Attending through Zoom: Jennifer Fung, John Marble, Emily Witkin, and Florence Wong.

Committee Members Absent: Jennifer Fung and Dr. Jennifer Pien.

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

Accessibility Assistance: Interpreter Andres, Interpreter Adriana, Captioner Anna, Captioner Carilyn, Support Eunice.

Legislative Office Representation: Tiffanee Jones from Assemblymember Lori D. Wilson's Office

Guests Attending: Sandy Chin, Khushboo Chabria, Christy Lam-Julian, Sara Desumala, Teresa Nold.

4:05p Chair Elizabeth Grigsby called the meeting to order. Valerie Buell reviewed the housekeeping and took roll call of RAC members.

4:11p Public Comments: Elizabeth Grigsby asked for public comments. Highlights included:

- Khushboo Chabria shared:
 - Invited here by RAC member, John Marble, and am representing Neurodiversity Pathways. This February we are going to be hosting our spring cohort of our career readiness training: a 17-week, learn-by-doing, online course for neurodivergent jobseekers. The program is covered by the Department of Rehabilitation, and it is may also covered by the Regional Center.
- Tiffanee Jones, District Director from Assemblymember Lori D. Wilson's Office, out of Solano County, District 11. Serves part of Contra Costa County. We partner with other assembly members in Contra Costa County to do things on behalf of constituents.



- Assemblymember Wilson is currently the chair of the Legislative Black Caucus, and this is her last year chairing that body of legislators. She is also now the Chair of Transportation and Emergency Preparedness for the state.
- She also serves on Appropriations, Budget, Housing and Community Development, Public Safety, Climate, Crisis Response, Emergency, Energy and Transportation, Local Public Safety, Ports and Goods, Students with Disabilities, Streamlining Services for Victims of Interpersonal Violence.
- We are still looking for legislation to be able to support, so if you all have legislation that we need to be looking at, if you have spot bill ideas, please get that to me by the 19th.
- Christy Lam-Julian shared:
 - I just found out about the State Council. Family advocate and resource parent at West Contra Costa Unified, and helping other families navigate the system.
 - Families have challenges getting through the regional center and getting case managers to respond. Is there a network or community that we can get connected with to help navigate this system?
 - Sheraden Nicholau invited Christy Lam-Julian to contact our office and book a meeting to talk about these needs and Valerie Buell put her email address in the chat to request to be added to the eblast list.

4:28p Continuation of the Bay Area RAC Topics & Potential Projects for Exploration for Fiscal Year 2023-24.

- Sheraden Nicholau gave a brief review of the purpose of this meeting, the accomplishments of the RAC over the last year, and the draft list of topic areas of exploration shared in the November RAC meeting and through email (listed below):
 - Collaborate with the San Mateo Commission on Disabilities regarding the statewide Caregiver Abuse Registry.
 - Involvement and advocacy for our community regarding social and recreational programing.
 - o The Supportive Decision-Making Technical Assistance Program.
 - The State Council Storyteller's Project.
 - Involvement in advocacy for our community with the Metropolitan Transportation Commission.
 - Involvement and advocacy for our community with the Association of Bay Area governments.
 - Involvement and advocacy for our community with the Bay Area Housing Finance Authority.
- Sheraden asked for anything else members would like to add to the list and took notes, shown on screen, throughout the brainstorming session, that summarized comments and allowed RAC members to review as the discussion went along.



Noted Suggestion highlights are:

- Marla Silversmith:
 - Regional center recruitment, retention, and support of case managers and staff, as well as timelines such as a time study to see the rate of compliance in responding to requests and calls from clients and potential clients.
 - Intersectionality.
 - Big areas of focus like bay area housing, transportation, are things that affect all of the community.
- Elizabeth Grigsby:
 - Accountability for regional center staff: When people call the regional center, they need to be able to talk to someone or be directed to someone who can answer their questions. If clients and/or their family advocates cannot reach anyone, the regional center should be held accountable.
 - Healthcare access for people with mobility needs and mobility equipment including reproductive care and other care, medical setting physical access.
- John Marble:
 - Barriers to system navigation and expanding opportunities with state programs, particularly around employment:
 - Figuring out what the barriers for job seekers. Esp. for those who are enrolled in the Department of Rehabilitation (DOR) but are not regional center clients.
 - Barriers with qualifying for services, but unable to get/access those services.
 - Navigating job development and coaching supports for civil service jobs / government jobs.
 - This could be folded into housing and other services.
- Florence Wong:
 - Tracking companies with a better record of hiring people with disabilities and invite them to present their strategies and best practices to use as a model that other private sector companies can follow.
 - (Sheraden followed up) There are some national models, some national organizations that do just that. So, there are some good practices out there we can look at if this ends up being a focus of the RAC. (Sheraden put information about The Employment First Office in the chat and gave a summary about the office)
 - We may have a RAC member attend the meetings of the Transportation Commission and Housing Authority virtually or just monitor what they are doing and perhaps make public comments at their meetings and report back to the RAC.
- Emily Witkin:



- Barriers in medical healthcare that apply to a larger portion of the community like reproductive healthcare. General healthcare equity and access.
- The Storyteller's Project can be something we do but not necessarily a priority.

Sheraden notified the RAC members the notes would be updated and sent to all RAC members and a vote on the priorities will be put on the agenda for February.

5:22p Other Announcements: No one had any announcements.

5:23p Meeting Adjourned.



State Council on Developmental Disabilities (SCDD) Bay Area Regional Advisory Committee (RAC) Meeting February 28, 2023, Minutes DRAFT

This meeting was hybrid--held in person, and through Zoom (video call or call-in) Location: Roosevelt Elementary School, Heron Hall, 1151 Vancouver Ave, Burlingame, CA 94010 Link: https://us02web.zoom.us/j/87271918131?pwd=cG1LNW9FWDV6bkViMEw5eVUreG5idz09 Meeting ID: 872 7191 8131 Passcode: 723838

Committee Members Attending in-person: Elizabeth Grigsby, Marla Silversmith, and Florence Wong

Committee Members Attending through Zoom: Jennifer Fung, John Marble, Dr. Jennifer Pien, and Emily Witkin.

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

Accessibility Assistance: Interpreter Adriana, Interpreter Andres, Captioner Carilyn, Captioner Marie

Legislative Office Representation: Assemblymember Tim Grayson, Diana Sanchez from Assemblymember Tim Grayson's Office, Leslie Bulbuk from Assemblymember Marc Berman's Office, Aidan Lynch from Assemblymember Damon Connolly's Office, Stella Gryler from Assemblymember Buffy Wicks's Office, Michelle Henry from Assemblymember Rebecca Bauer-Kahan's Office, Nicholas Hargis from Representative Anna Eshoo's Office, and Katie Jaycox from Representative Josh Harder's Office.

Guests Attending in-person: Jerry Grace, and Sara Desumala

Guests Attending on Zoom: Lisa Kleinbub, Patrick McKay, Vi Ibarra, Aparna Kommineni, Teresa Carol, Ernesto De La Torre, Nicola Ifill-Fraser, Nora Lewis, Caniya Johnson, Will Sanford, Tyler, and Erika M.

5:33p Chair Elizabeth Grigsby called the meeting to order. Valerie Buell took roll call of RAC members and confirmed a quorum was present.

- **5:34p** Approval of Meeting Minutes for November 29, 2023: Moved: Elizabeth Grigsby Seconded: Marla Silversmith Roll Call Vote:
 - Ayes: All ayes



5:37p Public Comments: Elizabeth Grigsby asked for public comments. Highlights included:

- Aidan Lynch from Assemblymember Damon Connolly's Office:
 - Gave overview of services provided by their office and Assembly District 12 in Marin County and part of Sonoma County.
 - Invited constituents to reach out if they have questions about legislation or line items in the budget; he included contact information in the chat.
- Nicholas Hargis from Representative Anna Eshoo's Office:
 - Gave overview of Congressional District served in San Mateo County and part of San Jose, Los Gatos, and Saratoga.
 - Shared he attended the groundbreaking of Mitchell Park Place, a new housing development in Palo Alto, and that 25 of the 50 apartments are being reserved for people with Intellectual Developmental Disabilities (IDD), and more details about the project. (State Council staff were in attendance as well).
 - Representative Eshoo continues to solicit support for her Communications Video and Technology Accessibility Act which would strengthen the closed captioning standards and audio description standards across the board and give government the ability to implement accessibility standards in emerging technologies.
- Leslie Bulbuk from Assemblymember Marc Berman's Office:
 - Shared their office is also excited about the Mitchell Park Place housing project and shared contact information in chat.
- Assemblymember Tim Grayson shared the following:
 - Shared his history as an advocate for the IDD community through his relationship with his sister, who is a person with Down Syndrome.
 - His work with former Assemblymember Jim Frazier, who has been an IDD advocate in and out of the legislature.
 - His work to fight for funding for Special Olympics, and experience attending those events when growing up.
 - Bills authored:
 - AB 2821 which would require higher education faculty and staff to train on compliance with disability accommodations for students with disabilities.
 - AB1914 which would establish a standardized curriculum for a certification program that is tailored to professionals that serve individuals with developmental disabilities as well.
 - AB624 (authored last year and vetoed) would have covered the cost of diagnostic assessments for disability accommodation for students with disabilities.
 - Stressed his continued commitment to advocacy for the IDD community.



5:52p Sheraden Nicholau introduced the panel of speakers for the Specialty Health Ambassador Program: Nicola Ifill-Fraser, Ernesto De La Torres, and Nora Lewis, who gave their presentation.

- Ernesto De La Torres shared:
 - The Community Outreach Program was built with a grant from the Department of Developmental Services and is comprised of eleven ambassadors or community health workers with diverse backgrounds and personal lived experience with IDD.
 - The main goal of the program is for health ambassadors to connect individuals with IDD to services, with a specific focus on outreach to historically marginalized communities, including Black, Indigenous, and other People of Color (BIPOC) communities across Contra Costa County.
 - After collecting contact information, health ambassadors follow up with community members to determine if they were able to connect with the Regional Center of the East Bay and/or other services of need.
 - Health ambassadors are part-time, about 20 hours a week, and are contract based, with rates based on competitive wage for health workers, front line health workers, and community health workers in Contra Costa County.
 - Ambassadors are trained to identify individuals who may fall into one of three categories: Eligible but unaware of services, underserved, or disconnected from service systems and in need help reconnecting.
- Nora Lewis shared:
 - The program bridges the gap between people with IDD and services by the regional center and other systems, meeting them where they are by going to food banks, places of worship, and events they may attend.
 - Training for the program, called the Work Force Essential Training, is held on Tuesdays and Thursdays, 10:30 AM to 12:00 PM at the Pittsburgh Health Center.
 - Connections have been built with groups like Care Parent Network and La Familia, to foster collaboration and support.
- Nicola Ifill-Fraser shared the challenges and some outcomes:
 - Understanding it is important for employers (the county) to address the individual needs of the health ambassador, especially when they have diverse learning styles, abilities, and challenges.
 - Primary areas for outreach are low-income areas.
 - It is important that health ambassadors can speak the languages in areas of need.
 - Participation resistance still happens, as there are still biases against people with IDD that persist among communities.
 - Transportation logistics are difficult to manage as many health ambassadors do not have cars. Navigating the target areas and relying on public transportation is especially difficult for early morning and late evening outreach events.



- Approaches are customized to fit the culture of each community, such as providing materials and trainings in the preferred language for, as an example, Spanish speaking communities.
- Peer to Peer learning is fostered to create an environment where health ambassadors can share experiences with each other.
- Leveraging unique strengths of each health ambassador while identifying areas where they need support helps ambassadors to face the challenges of engaging with communities.
- After attending 116 engagements, we have engaged over 5700 individuals. 25% of follow-up sessions happened six months after.
- 20 trainings have been provided to community members with two presentations sharing lessons learned to stakeholders.
- Sheraden informed attendees the Power Point of this presentation will be posted to the SCDD Bay Area Office web page.

6:17p Discussion and vote on RAC Priorities that is a continuation and conclusion of the previous meetings:

- Valerie Buell shared screen so everyone could see the list of seven topics of discussion and vote for two of the seven to be a focus for the 2024-2025 State Fiscal Year.
- Sheraden reviewed with attendees the list of seven topics and led discussion on each:
 - 1. Healthcare access for people with IDD
 - 2. Services, systems navigation, and barrier removal for job seekers and employees with disabilities.
 - 3. Intersectional advocacy.
 - 4. Statewide Caregiver Abuse Registry.
 - 5. Involvement and advocacy for Social and Recreational Programming.
 - 6. Regional Center service capacity and quality.
 - 7. Supported Decision Making (SMD) Technical Assistance Program.
- Valerie Buell took a roll call vote for each topic.
 - Jennifer Fung voted for Healthcare access for people with IDD and Intersectional Advocacy.
 - Elizabeth Grigsby voted for Intersectional Advocacy and Supported Decision Making.
 - John Marble voted for Services, systems navigation, and barrier removal for job seekers and employees with disabilities, and Healthcare access for people with IDD.
 - Marla Silversmith voted for Statewide Caregiver Abuse Registry and Supported Decision Making.
 - Emily Witkin voted for Healthcare access for people with IDD and Involvement and advocacy for Social and Recreational Programming.



- After this first vote, **Healthcare access for people with IDD** will be the first topic. Another discussion was held about how to decide the remaining topic. John Marble suggested a fresh vote on all remaining topics.
 - Moved: John Marble
 - Seconded Elizabeth Grigsby
 - Vote: All Ayes
- Discussion was held on the remaining six topics, then Valerie Buell did a second roll call vote for topic choice.
 - Jennifer Fung voted for Intersectional Advocacy.
 - Elizabeth Grigsby voted for Supported Decision Making
 - John Marble voted for Services systems navigation, and barrier removal for job seekers and employees with disabilities.
 - Marla Silversmith voted for Statewide Caregiver Abuse Registry.
 - Emily Witkin voted for Involvement and advocacy for Social and Recreational Programming.
 - Florence Wong voted for Statewide Caregiver Abuse Registry.
- After the second vote, Statewide Caregiver Abuse Registry will be the second topic.

6:52p Legislative Office Comment after the presentation:

- Sara Desumala shared she is with People First and is the secretary for the Northern Alameda County chapter and is the president of the San Francisco chapter.
- Katie Jaycox from Representative Josh Harder's Office shared:
 - Rep. Harder is currently working on making sure we have a federal budget, and we keep the government open.
 - He's cosponsored the Alice Cogswell and Anne Sullivan Macy Act that would improve services and education opportunities for students who are deaf, hard-ofhearing, blind, and visually impaired.
 - He is on the House Appropriations Committee and subcommittee that oversee all healthcare activities and supports Health and Human Services funding as well as making sure they set aside funding for disability services.
 - He has been focusing on the shortage of doctors, specialty doctors, and therapists in his district and sponsored a bill to bring more therapists and address the mental health crisis in San Joaquin County and Contra Costa County.
 - Their office welcome constituents to reach out with any questions or concerns and shared contact information in the chat.

6:55p Community Partner Reports:

People First Highlights:

• Jerry Grace read the report from Patrick McKay for Bay Area People First (BAPF):



- The last meeting had a presentation on the National Core Indicators surveys, by SCDD staff, Ron Usac.
- The next meeting is April 17th from 4:15 PM to 5:15 PM. All are welcome.

Regional Center Report Highlights.

- Lisa Kleinbub gave the report for Regional Center of the East Bay (RCEB):
 - RCEB is working on a strategic plan for the area after collecting data through surveys and reviewing that data with the board. There will be five focus areas which include person-centered planning and the work culture of RCEB.
 - Community meetings around Purchase of Service (POS) are scheduled around the Bay Area to hear from the community. RCEB is working on updating POS policies and updating procedures for case managers to follow those policies.
 - John Marble asked about previous discussions regarding the difficulties many have had with becoming clients and could Lisa report on success in improving access. Lisa shared they are calling that focus area Progress Improvement and the work they are doing to be more transparent and less complicated with this new plan.

Developmental Disabilities (DD) Councils Report Highlights:

- Vi Ibarra gave the report for the Contra Costa County Developmental Disabilities Council:
 - Both the Alameda County Developmental Disabilities Council and the Contra Costa Developmental Disabilities Council will have a joint transition conference and resource fair at the College of Alameda. Registration is now open, and flyers are in the chat as well as the registration link.
 - There are upcoming presentations for community members who may not have attended the council meetings before and may be confused by conversations, so this is a way to give updates in a community conversation. They will take place in March and April and the flyer is in the chat.
 - The Joint Awards event for both counties, at the Pleasant Hill Community Center, is scheduled for June 6th and the county councils are asking for nominations. Nomination forms will be sent out in March.

7:19p Member Reports: RAC Members and Councilmembers reported on their regional and statewide advocacy work and priorities. Highlights include:

- Jennifer Fung:
 - Jennifer has applied for the SCDD Statewide Self-Advocacy Leadership Academy (SALA) and is one of two applicants from the Bay Area. These advocates will develop more advanced self-advocacy leadership skills to dive into different systems and work on systems change.
- Elizabeth Grigsby:



 Has been working with an organization for the past month, Valor US, located in Southern California. They've been going to different disability communities talking about sexual assault violence against people with disabilities. Regional centers and other agencies need to work together to combat the violence and to make sure victims are believed when they tell their stories.

• John Marble:

- Thank you all who shared out the Neurodiversity Pathways Program (where John is an instructor). We're in week two now. It is completely full of adults who are either transitioning to employment or have been in employment for a long time but ready to move forward.
- On March 19th the book John coauthored, "Neurodiversity For Dummies", will be published by Wiley Publishing. Link posted in the chat.

Marla Silversmith:

- Had the honor of presenting to a community advisory committee for special education with a parent group special educational plan area on transitioning out of high school into adult life.
- Marla's district has brought two other districts together to expand doing more inclusive sports. She will be present to see the celebration of student athletes tomorrow.

• Emily Witkin

 Has recently experienced difficulties navigating the healthcare system, specifically around access to medical imaging. Many people need accommodations for medical imaging, such as sedation to undergo imaging procedures. Outpatient clinics will not provide that.

Florence Wong:

- The San Mateo County (SMC) Commission on Disabilities, in collaboration with all the high school districts in San Mateo County, held their Transition to Independence Fair recently. SCDD had a table there. It was well attended with a lot of positive feedback.
- The SMC Commission on Disabilities several discussions of importance on the updated Brown Act meeting rules impacting the IDD community, and the lack of reliable and safe public transportation.

7:42p Other Announcements:

- Sara Desumala suggested using the Alameda County Developmental Disabilities Council location for a future RAC meeting.
- Jerry Grace reminded attendees that election day is March 5th.
- Aparna Kommineni shared she met Regional Center of the East Bay Executive, Lisa Kleinbub, and they discussed concerns with getting vendors who provide social and recreational services, and this is something they are working on and would love to connect with others interested in making this happen.



Valerie Buell shared; the next RAC meeting is on April 24th, 2024. It will be a hybrid meeting.

7:52p Meeting Adjourned.



Healthcare & People with Disabilities: Systemic Considerations & Practical Tools for Equity





The State Council

The State Council on Developmental Disabilities (SCDD) is established by state and federal law as an independent state agency to ensure that people with developmental disabilities and their families receive the services and supports they need. We do so through:

- ➤Systemic change
- Educating public entities and community members
- Moving forward disability related legislation
- ≻Increasing capacity for equity and inclusion





The State Council's Work: Advocacy, Capacity Building, Systems Change

- Systems navigation, technical assistance, consult
- Coalitions and Committees
- Trainings / Education & Outreach
- Grants & Sponsorships
- Policy, legislation, implementation





Some of What We Know... (1 of 2)

- 1 in 4 working age adults with disabilities in the U.S. do not have a usual healthcare provider. 1 in 4 adults with disabilities 18 to 44 years have an unmet health care need because of cost in the past year. (2023, CDC)
- ➤4 in 10 adults with disabilities experience unfair treatment in healthcare setting, at work, or when applying for public benefits in 2022. (2023, Urban Institute & Robert Wood Johnson Foundation)
- ▶1 in 5 adults with disabilities 45 to 64 years did not have a routine check-up in the past year. (2023, CDC)
- Nearly 2/3 of U.S. physicians report feeling unprepared don't feel like they have the training or skills to properly care for people with disabilities. (2024, IEC National Roadmap)



Some of What We Know... (2 of 2)

- Studies estimate that between 70% and 85% of cases of abuse against disabled adults go unreported. (2003, DRC).
- Individuals with IDD and a psychiatric disability / mental health condition (cooccurring) are often underserved, lack access to treatment, and may experience discrimination when they try to access services.
 - Most professionals accept that roughly 35% of persons with intellectual disabilities also experience mental health challenges. (NADD, 2022)



Reflecting on Systemic Inequities & our History

History tells of layers of discrimination against people with disabilities in medical and healthcare settings. E.g.:

- Eugenics movement, which included forced sterilization and euthanasia
- Institutionalization
- Refusal of care
- The false belief that disabilities are only something to be cured (medical model v. social model of disability)



Panning Out: Big Picture for Health & Healthcare Equity (1 of 2)

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.



Panning Out: Big Picture for Health & Healthcare Equity (2 of 2)

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.



Key Issues: Systemic & Unconscious Bias

- The importance of bioethics and medical ethics being connected and informed by disability rights and disability justice movements.
- Accessibility barriers continue to exist- physical, attitudinal, programmatic, systemic.
- Many patients with disabilities experience unconscious bias when receiving care, and when discussing their care with providers. E.g.:
 - False assumptions about quality of life
 - Providers' lack of training and overall knowledge about disability
 - Institutionalized ableism
 - Providers' assumptions of capacity and consent



Key Issues: Intersectional Disparity

Patients with disabilities may experience healthcare access and healthcare quality disparities related to their disability, their race or ethnicity, their gender, their age, and/or their income.

Overlapped identities mean that a person's experiences with inequity or lack of access may be more complex or different than another's.

We need to develop more capacity to address social determinants of health in public health, health care, and in civil rights work.



Looking Forward: Practical Tools & Strategies for Equity

- Ensure leadership bodies, advisory bodies, and community coalitions include people with disabilities, and ensure accessibility for full participation.
- Ask orgs and schools that teach or represent healthcare providers to include disabilities specific training / coursework / practicum / continuing medical education (CME).
- Use content, stories, quotes, case studies, and input from the disability community to educate, train, and create systems change.
- Look at scaling promising models, like Specialty Health Ambassadors Programs.



Tools that Patients with Disabilities, their Allies & Professionals Need to Know

- Person-Centered Planning & Health Profiles
- Supported Decision Making
- Advance Medical Directive
- Power of Attorney
- Welfare & Institutions Code (e.g. WIC 4655, WIC 4541)
- Resources and Supports in their local community



What the Community Needs from Allies & Professionals

- Educated and trained healthcare providers, administrators, advocates
- Plain Language & Easy Read resources / forms / signs / websites
- Accessible spaces, equipment for Access and Functional Needs (AFN)
- Process & procedures with access, equity, and adaptability in mind
- Cultural humility



Bills to Check Out This Legislative Cycle (1 of 2)

AB 2043 (Boerner) Medi-Cal: Nonmedical & nonemergency medical transportation. Requires the Department of Health Care Services to require Medi-Cal managed care plans to contract with public paratransit service operators who are enrolled Medi-Cal providers. Location: Committee Health

SB 1384 (Dodd) Power Wheelchair Repair. Increases accessibility and affordability for wheelchair users, making it easier for consumers to maintain their devices and keep them in good working condition, by requiring manufacturers to provide information, tools, and replacement parts to an owner or repair provide.

Location: Committees Business Professions & Economic Development & Judiciary

AB 2753 (Ortega) Rehabilitative and habilitative services: Durable medical equipment and services. Requires health plans to include coverage of durable medical equipment, services, and repair. Location: Committee on Health



Bills to Check Out This Legislative Cycle (2 of 2)

AB 1977 (Ta) Health care coverage: Behavioral diagnoses. Does not allow a healthcare plan to require a person who is already diagnosed with developmental disorder or autism to be re-evaluated to maintain healthcare coverage for their condition. Why this is important: These conditions are for life, they do not change or go away, getting re-tested just creates a risk of losing this important healthcare insurance. Location: Committee Health

AB 2510 (Arambula) Health care coverage: Behavioral diagnoses. Requires DDS to create a new program in the regional centers to improve dental care services to people with developmental and intellectual disabilities. These new programs also must reduce the need for regional center consumers to receive dental treatment using sedation and general anesthesia. Location: Committees on Human Services and Higher Education

SB 483 (Cortese) Prone Restraints. Prohibits prone restraints from being used on students. Location: Passed Senate – now in Assembly



The Power of Partnerships: Advocacy & Inclusion Must be Intersectional!

- Representation matters. How are you ensuing you hear underserved voices?
- The power of collective advocacy and rights work in healthcare and *in all systems*.
- Lifelong learning and growing to recognize and dismantle oppression in all forms, and to increase accessibility and equity.

NEW! Disability advocates fight to be included in health equity research, and succeed in 2023 The designation as a health disparity population allows for more funding and research into the health equity barriers disabled people face: <u>National Advisory Council on Minority Health and Health Disparities</u> (NACMHD) Working Group on Persons Living with Disabilities (nih.gov)



Resources to Build Capacity & Access: From Community Partners

State Council health related and other resources: <u>https://scdd.ca.gov/resources/</u>

Healthcare access resources and data from DREDF, https://dredf.org/healthcare-access

Research, training, clinical tools, document library, and advice from self-advocates to their health care professionals: <u>https://odpc.ucsf.edu/</u>

Stanford Medicine Alliance for Disability Inclusion and Equity (SMADIE): <u>https://med.stanford.edu/smadie.html</u>

NPR article on Tradeoffs health policy podcast episode, *For Patients with Disabilities, this Doctor Prioritizes Independence - and Fun*: <u>https://www.npr.org/sections/health-shots/2024/03/26/1240827697/for-patients-</u> <u>with-disabilities-this-doctor-prioritizes-independence-and-fun</u>



Resources to Build Capacity & Access: Data and Roadmaps

Institute for Exceptional Care's National Roadmap for Disability-Inclusive Healthcare: <u>www.inclusivecareroadmap.org</u>

NIH National Institute on Minority Health and Health Disparities' National Advisory Council on Minority Health and Health Disparities (NACMHD) Working Group on Persons with Disabilities: <u>https://nimhd.nih.gov/about/directors-corner/messages/health-disparities-</u> <u>population-designation.html</u>

Centers for Disease Control and Prevention. Disability and Health Data System (DHDS) updated May 2023. Available from: <u>http://dhds.cdc.gov</u>



Resources to Build Capacity & Access: In Journals

Kripke, C. C. (2017). Patients with Disabilities: Avoiding Unconscious Bias When Discussing Goals of Care. *American Family Physician*, 96(3). Retrieved from <u>https://escholarship.org/uc/item/692882h1</u>

Yee, S., Breslin, M.L., Goode, T., Havercamp, S., Horner-Johnson, W., Iezzoni, L., & Krahn, G. (2018). <u>Compounded Disparities: Health Equity at the Intersection of</u> <u>Disability, Race, and Ethnicity</u>. The National Academies of Sciences, Engineering and Medicine (NASEM).



Resources to Build Capacity & Access : Disability Justice

Disabled And Here, a disability-led stock image and interview series celebrating disabled Black, Indigenous, people of color (BIPOC) https://affecttheverb.com/disabledandhere/

"What Is Disability Justice?" By Sins Invalid

https://www.sinsinvalid.org/news-1/2020/6/16/what-is-disability-justice

"This is Disability Justice" by Nomy Lamm for The Body is Not an Apology <u>https://thebodyisnotanapology.com/magazine/this-is-disability-justice/</u>



Resources to Build Capacity & Access: How To / Guides

Autistic Self-Advocacy Network (ASAN) Easy Read Guide: <u>https://autisticadvocacy.org/resources/accessibility/easyread/</u>

Center for Plain Language's Five Steps to Plain Language: https://centerforplainlanguage.org/learning-training/five-steps-plainlanguage/

Learning Tools from the Center for Plain Language: <u>https://centerforplainlanguage.org/learning-training/</u>



Image from Disabled And Here (affecttheverb.co m)

Healthcare Day, SCDD for LPA 2024



To:Regional Advisory Committee (RAC) Members & Interested PartiesFrom:State Council on Developmental Disabilities' Bay Area Regional OfficeDate:April 4, 2024

Re: Projected 2023-2024 Schedule of State Council Bay Area Regional Advisory Committee (RAC) Meetings

Members of the public are welcomed and encouraged to participate in these Bay Area Regional Advisory Committee (RAC) meetings. Accessible formats of all agenda and materials can be found at least 10 days prior to the meeting at: <u>www.scdd.ca.gov/bayarea/</u>.

Starting January 1, 2024, these meetings comply 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 a meeting that were granted a reasonable accommodation per the Americans with Disabilities Act. 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.

All committee meetings are open to the public.

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

September 27, 2023	Ed Roberts Campus: 3075 Adeline Street, Berkeley, CA 94703 Main Floor, Osher Foundation Education Center
November 29, 2023	Virtual Meeting on Zoom
February 28, 2024	Roosevelt Elementary School, Heron Hall, 1151 Vancouver Ave, Burlingame, CA 94010
April 24, 2024	Alameda County Developmental Disabilities Council, Oak Conference Room, 1100 San Leandro Blvd, San Leandro, CA 94577
June 26, 2024	Marin County Office of Education, 1111 Las Gallinas Ave, San Rafael, CA 94903

No meetings in July or August 2024



Para: Miembros del Comité Asesor Regional (RAC) y partes interesadas
De: Oficina Regional del Área de la Bahía del Concilio Estatal de Discapacidades del Desarrollo
Fecha: 4 de abril de 2024
Re: Calendario proyectado para 2023-2024 de las reuniones del Comité Asesor Regional del Área de la Bahía

Los miembros del público son bienvenidos y alentados a participar en estas reuniones del Comité Asesor Regional del Área de la Bahía (RAC). Los formatos accesibles de todos los programas y materiales se pueden encontrar al menos 10 días antes de la reunión en: <u>www.scdd.ca.gov/bayarea/</u>.

A partir del 1 de enero de 2024, estas reuniones cumplen con las Secciones 11123.1, 11123.2 y 11125(f) del Código de Gobierno. Los miembros pueden estar físicamente presentes en uno o más lugares de teleconferencia. Puede haber miembros del organismo público que están participando de forma remota en una reunión a la que se le concedió un ajuste razonable según la Ley de Estadounidenses con Discapacidades. Las personas con discapacidades que requieren formatos alternativos accesibles de la agenda y materiales relacionados y/o auxiliares/servicios para participar en cualquier reunión deben contactarnos a bayarea@scdd.ca.gov o llamarnos al **510-286-0439** o **bayarea@scdd.ca.gov** al menos cinco (5) días hábiles antes de la reunión.

Todas las reuniones del comité están abiertas al público.

Para todas las reuniones: Oportunidad de red 5:15 pm a 5:30 pm y las reuniones del RAC son de 5:30 pm a 8:00 pm.

27 de septiembre de 2023	Campus Ed Roberts: 3075 Adeline Street, Berkeley, CA 94703 Planta Principal, Centro de Educación de la Fundación Osher
29 de noviembre de 2023	Reunión virtual en Zoom
28 de febrero de 2024	Escuela Primaria Roosevelt, Heron Hall, 1151 Vancouver Ave, Burlingame, CA 94010
24 de abril de 2024	Concilio de Discapacidades del Desarollo del Condado de Alameda, Sala de Conferencia Oak, 1100 San Leandro Blvd, San Leandro, CA 94577
26 de junio de 2024	Oficina de Educación del Condado de Marin, 1111 Las Gallinas Ave, San Rafael, CA 94903

No hay reuniones en julio y agosto de 2024

Revisado: 4/5/2024

"The Council advocates, promotes & implements policies and practices that achieve self-determination, independence, productivity & inclusion in all aspects of community life for Californians with developmental disabilities and their families."