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

Wednesday, February 23, 2022
Networking 6:15-6:30 PM  Meeting 6:30-9:00 PM
This is a Teleconference and Zoom meeting only.

Per Executive Order N-29-20, teleconferencing restrictions are waived during the COVID-19 pandemic. Members of the public may participate 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 by Zoom:
https://us02web.zoom.us/j/87331059775?pwd=eE0yTkUxb28rOERyamo2dzd2NXU4Zz09
Meeting ID: 873 3105 9775  Passcode: 699582

Or by Telephone, US Toll-free: (877) 853-5257 or (888) 475-4499
Meeting ID: 873 3105 9775  Passcode: 699582

Collaboration is key! We invite members of the community to share input, issues and concerns. All are welcome. Featured this meeting: Updates and COVID impacts on disability services within Regional Center funded services, IHSS, and school district funded services; RAC Member updates, and more!

Information: Pursuant to Government Code Sections 11123.1 and 11125(f) and Executive Order N-29-20. 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.
De acuerdo con la Orden Ejecutiva N-29-20, las restricciones de teleconferencia no se aplican durante la pandemia de COVID-19. Los miembros del público pueden participar por teléfono o Zoom desde cualquier lugar. Los formatos accesibles para toda la agenda y los materiales se pueden encontrar al menos 10 días antes de la reunión a: www.scdd.ca.gov/bayarea/.

ÚNETE A LA REUNIÓN POR ZOOM:
https://us02web.zoom.us/j/87331059775?pwd=eE0yTkUxb28rOERyamo2dzd2NXU4Zz09
ID de la reunión: 873 3105 9775, Contraseña: 699582

O

ÚNETE POR TELECONFERENCIA: (SOLO VOZ)
Llamar al número: 1 888 475 4499 o 1 877 853 5257,
ID de la reunión: 873 3105 9775, Contraseña: 699582

¡La colaboración es clave! Invitamos a los miembros de la comunidad a compartir opiniones, problemas e inquietudes. Todos son bienvenidos. Destacado en esta reunión: Actualizaciones e impactos de COVID en los servicios para discapacitados dentro de los servicios financiados por el Centro Regional, IHSS y servicios financiados por el distrito escolar; Actualizaciones para miembros de RAC, ¡y más!

Información: En cumplimiento de las secciones 11123.1 y 11125(f) del Código de Gobierno y la Orden Ejecutiva N-29-20 las personas con discapacidades que requieran formatos alternativos accesibles de la agenda y materiales relacionados de la reunión y / o ayudas / servicios auxiliares para participar en esta reunión deben comunicarse al 510-286-0439 o bayarea@scdd.ca.gov al menos 5 días hábiles antes de la reunión.
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES (SCDD)
BAY AREA REGIONAL ADVISORY COMMITTEE (RAC) MEETING & COMMUNITY OUTREACH

NOTICE & AGENDA*

Date       Wednesday, February 23, 2022

Time       Networking 6:15pm – 6:30p, Meeting 6:30pm – 9:00pm

Locations  This is a teleconference and Zoom meeting only.

There is no physical location being made available to the public. Per EXECUTIVE ORDER N-29-20, teleconferencing restrictions are waived during the COVID-19 pandemic. Regional Advisory Committee members are not required to list their remote locations. Members of the public may participate 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/. This meeting will be live captioned and have Spanish interpretation.

Join by Zoom:
https://us02web.zoom.us/j/87331059775?pwd=eE0yTkUxb28rOERyamo2dzd2NXU4Zz09
Meeting ID: 873 3105 9775 Passcode: 699582

Or by Telephone, US Toll-free: (877) 853-5257 or (888) 475-4499
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For more information, contact the State Council on Developmental Disabilities Bay Area Regional Office, 510-286-0439 or bayarea@scdd.ca.gov.
Pursuant to Government Code Sections 11123.1 and 11125(f) and Executive Order N-29-20 (Executive Order can be found by typing https://www.gov.ca.gov/wp-content/uploads/2020/03/3.17.20-N-29-20-EO.pdf into your web browser), 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 510-286-0439 or email bayarea@scdd.ca.gov, at least 5 (five) business days prior to the meeting.

6:30p Call to Order
Introductions / Establishment of Quorum

6:35p Approval of the December 2021 Meeting Minutes

6:40p 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.
6:55p Panel: Updates and COVID Impacts on Disability Services

Hear an update on the impacts of the pandemic on disability services, including Regional Center funded services, In-Home Supportive Services (IHSS), and school districted funded services. Panelists include Lisa Kleinbub, Executive Director of Regional Center of the East Bay; Marla Silversmith, Assistant Superintendent, Educational Services, Burlingame School District; and Eric Zigman, Executive Director of Golden Gate Regional Center. Other panelists TBD.

7:40p Additional Legislative Office Comments

An invitation for legislative offices in attendance to provide brief statements, comments on emerging issues, or updates.

7:50p Community Reports

- People First Report
- Regional Center Reports
- County Developmental Disabilities Councils Reports

8:15p 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.

8:50p Other Announcements
& Agenda Items for Future Meetings

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

9:00p Meeting Adjourned

*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.
CONSEJO ESTATAL DE DISCAPACIDADES DEL DESARROLLO (SCDD)
REUNIÓN DEL COMITÉ ASESOR REGIONAL (RAC) DEL ÁREA DE LA BAHÍA Y ALCANCE COMUNITARIO

NOTICIAS Y AGENDA*

De acuerdo con la Orden Ejecutiva N-29-20, las restricciones de teleconferencia no se aplican durante la pandemia de COVID-19. Los miembros del público pueden participar por teléfono o Zoom desde cualquier lugar.

Los formatos accesibles para toda la agenda y los materiales se pueden encontrar al menos 10 días antes de la reunión a: www.scdd.ca.gov/bayarea/. Esta reunión será subtitulada en vivo y tendrá interpretación en español.

Únete a la reunión por zoom:
https://us02web.zoom.us/j/87331059775?pwd=eE0yTkUxb28rOERyamo2d2dzd2NXU4Zz09
ID de la reunión: 873 3105 9775 Contraseña: 699582

O únete por teleconferencia (solo voz): (877) 853-5257 or (888) 475-4499
ID de la reunión: 873 3105 9775 Contraseña: 699582
Para mas información, póngase en contacto con el Consejo Estatal de Discapacidades del Desarrollo al, 510-286-0439 o bayarea@scdd.ca.gov.

De conformidad con las Secciones 11123.1 y 11125(f) del Código Gubernamental y la Orden Ejecutiva N-29-20 (La Orden Ejecutiva se puede encontrar en el siguiente enlace https://www.gov.ca.gov/wp-content/uploads/2020/03/3.17.20-N-29-20-EO.pdf), las personas con discapacidades que requieran formatos alternativos accesibles de la agenda y los materiales de la reunión relacionados y/o ayudas/servicios auxiliares para participar en esta reunión deben comunicarse al 510-286-0439 o enviar un correo electrónico a bayarea@scdd.ca.gov, al menos 5 (cinco) días hábiles antes de la reunión.

Presentaciones / Establecimiento de Quórum Grigsby

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
sobre servicios para discapacitados

Escuche una actualización sobre los impactos de la pandemia en los servicios para discapacitados, incluidos los servicios financiados por el Centro Regional, los Servicios de Apoyo en el Hogar (IHSS) y los servicios financiados por los distritos escolares. Los panelistas incluyen a Lisa Kleinbub, Directora Ejecutiva del Centro Regional del Area de la Bahía; Marla Silversmith, Superintendente Asistente, Servicios Educativos, Distrito Escolar de Burlingame; y Eric Zigman, Director Ejecutivo del Centro Regional Golden Gate. Otros panelistas (por determinar)

Una invitación para que las oficinas legislativas presentes proporcionen declaraciones breves, comentarios sobre temas emergentes o actualizaciones.

- Informes de “Gente Primero”
- Informes del Centro Regional
• Informes de los Consejos de Discapacidades del Desarrollo del Condado

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

Y Puntos de la agenda para futuras reuniones  Grigsby

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

* 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
December 1, 2021 Minutes DRAFT

Main Location: This meeting was held through Zoom (video call or call-in only)
Link: https://us02web.zoom.us/j/89941399969?pwd=WW1HTjJSaXINLy9YR3c0YkNRSWpadz09
Meeting ID: 899 4139 9969    Passcode: 694578

Committee Members Attending through Zoom: Francisco Garcia, Elizabeth Grigsby, John Marble, Diane Millner, Pam Perls, Kate Rauch, Marla Silversmith, Florence Wong

Committee Members Absent: Sascha Bittner, Regina Woodliff

SCDD Staff: Sheraden Nicholau, Ron Usac, and Valerie Buell.

Accessibility Assistance: Interpreter Adriana, Interpreter Kim, Captioner Farrell, Captioner Verna

Legislative Office Representation: Assemblymember Marc Levine, Joan Lubamersky from Assemblymember Marc Levine’s office, Leslie Bulbuk from Assemblymember Marc Berman’s office, Elisa Yeung from Senator Scott Wiener’s office, Uche Uwahemu from Assemblymember Buffy Wick’s office

Guests Attending through Zoom: Gabby Romabiles, Lisa Kleinbub, Eric Zigman, Patrick McKay, Will Sanford, Shawn Costello, Sara Desumala, Angel Ng

6:30p Chair Elizabeth Grigsby called the meeting to order. Valerie Buell reviewed housekeeping: Zoom functions, chat, and interpretation services.

6:36p Approval of Meeting Minutes for September 29, 2021:
   Moved: Marla Silversmith
   Seconded: Francisco Garcia
   Roll Call Vote: All Ayes

6:37p Public Comments: Some highlights were:
   • Assemblymember Marc Levine:
     o It has been nine years since he was elected to the California Assembly, next year he is running for insurance commissioner.
     o The state will continue to find ways to accommodate and include individuals living with disabilities in conversations that will create a more accessible and inclusive California.
     o Legislative and budget commitments made:
       ▪ $10 Million allocated through the general fund toward ongoing funding for caregiver resource centers.
       ▪ $3.2 million will be allocated to support family resource centers as they develop a statewide program to provide mentorship, advocacy, and resource support to parents of individuals served by resource centers.
       ▪ $150 million to assist disabled individuals experiencing homelessness.
       ▪ Ongoing funding of $25 million to support this community.
$4 million for planning resources to produce an outcome-focused regional center operations funding program.

$106 will be appropriated over three years to strengthen older adults’ recovery and resilience from isolation and health impacts caused by the pandemic.

Eliminates suspensions for aging and disability resource connections and senior nutrition resulting in a total of $41.3 million in one-time and ongoing funding.

$10 million to increase competitive integrated employment opportunities for individuals in this community

Legislation signed by Governor Newsom that will be instrumental in protecting the privacy and wages persons living with disabilities in California:

- AB445 will remove the requirement for regional centers to collect certain private information from clients that is not necessary for centers to have in order to administer services.
- SB639 will phase out, by 2025, the use of sub-minimum wage certification programs, which now authorize employers to pay sub-minimum wages to employees with physical and/or mental disabilities

Will Sanford co-chair of the East Bay Legislative Coalition

- The Legislative Breakfast Town Hall will be on January 28th from 10:00 AM to 11:30 AM via Zoom. There will be a focus on future money pledged to our system.

Shawn Costello

- Not all businesses will allow you to work as much as you would like. I am currently working one day a week for two hours. I ask for more hours, but they (my employer) won’t let me.

6:49p Presentation:

Ron Usac gave a presentation on the National Core Indicators (NCI) Project:

- Overview of the purpose of the surveys, where they are being used, and what NCI is measuring.
- Overview of the Department of Developmental Services (DDS) and how they are involved.
- Overview of the process of data collection and the different types of surveys.
- Reminder that survey participation is voluntary and how participating can help future planning of services.
- English language surveys can be done online or on paper, all other languages available on paper.
- Reports can be found online, and anyone can look at the demographics, work, community, inclusion, relationships, and satisfaction. Data can be filtered by regional center or measure.

Comments, questions and answers:

- When will the new information be on the website?
  - It can take 3 years to put the report on the website.
- Do we ever let the people who took the survey know the material has been published?
  - At the bottom of the letter individuals receive it has a link to find the reports.
- Will NCI rewrite the survey before the next go around?
  - That is done every year.
- The idea of this survey is to learn from it and make changes. Looking at the data it shows what people need more information about, e.g. like how to report abuse or neglect.
It is important to look at how we compare nationally and how we compare to other regional centers.

7:25p Member Reports: RAC Members and Councilmembers reported on their regional and statewide advocacy work and priorities. Highlights (one or two updates) were:

- Francisco Garcia:
  - Working with the Spanish language community, focusing on self-determination and sharing information about the COVID vaccine.

- Elizabeth Grigsby:
  - There will be two public listening sessions to work on limited conservatorship reform in CA. The dates are not yet set, but there will be Spanish interpretation and captioning. After that a letter for the Council will be drafted, to be voted on in a special RAC meeting.

- Dianne Millner:
  - Currently serving on the Self-Determination local advisory committee and working on a subcommittee to put together a Bay Area website that will give information about the Self-Determination Program.

- Pam Perls:
  - Attended the Contra Costa Mental Health Commission and will be attending the Alameda Master Plan for Aging on Friday.

- Kate Rauch:
  - Retiring from the County and moving into various jobs. Will continue to reach out to people in Contra Costa County about issues.

- Marla Silversmith:
  - It is the 46th anniversary of IDEA (Individuals with Disabilities Education Act), and it helps general education teachers and others understand the barriers that need to be removed so every child can have access to the best education.

- Florence Wong:
  - San Mateo County Commission on Disabilities approved a tip sheet regarding medications for emergency go bags. It is now on the website.
  - On December 7th, at 10:00 AM, a subgroup of the Abuse Roundtable to look at steps to create a caregiver abuse registry.

7:42p Additional Legislative Office and/or RAC Member comments: Some highlights were:

- Eliza from Senator Scott Wiener’s Office
  - Senator Weiner supported bills that the State Council has also supported.
    - SB639 which will phase out sub minimum wage in CA.
    - SB52 which expands the Emergency Services Act to include in the public safety power shut off events.
    - AB323 which improves the health and safety of patients in skilled nursing facilities by holding the nursing home accountable for deaths that could have been avoided.
    - AB313 which improves the limited examination and appointment program through LEAP (Limited Examination and Appointment Program) by ensuring individuals with intellectual and developmental disabilities have more job opportunities in civil service.
    - Coauthor of AB118, which is for the Department of the Social Services Grant Pilot Program.
    - Coauthor of AB1400 which is California’s Medicare for All Program.
Housing remains the Senator's top priority, but the lack of the housing has been limiting what homes are available for individuals with developmental disabilities and their families.

8:04p Community Partner Reports:

- **People First**: Highlights from Patrick McKay, President Bay Area People First and of the Northern Alameda People First Chapter:
  - We had our Bay Area People First meeting today. We talked about the status of People First chapters in our region. We are hoping to start meeting in the future in a hybrid model to accommodate those who are not able to meet by Zoom.

- **Regional Center Report Highlights.**
  - Eric Zigman gave the report for Golden Gate Regional Center (GGRC):
    - The Department of Developmental Services has two initiatives going from the investments in this last budget around performance.
    - An employment workgroup is starting.
    - Last month, the GGRC Board of Directors had a presentation from Mary Lou Bourne, Person-Centered Planning National Expert, that consulted on the Center for Medicare and Medicaid Services (CMS), and talked about what was learned nationally during the pandemic, including the importance of technology.
  - Lisa Kleinbub gave the report for Regional Center of the East Bay (RCEB):
    - Ron Usac from the Bay Area Office provided a presentation about the NCI process for the Consumer Advisory Committee for RCEB.
    - Looking at NCI data: Housing stood out: 59% of the family members in our area were concerned about the future of their family member regarding housing.
    - We are making progress on developing new resources for people in crisis.
    - Alameda and Contra Costa counties are moving away from two plan Medi-Cal models and to a one plan model starting January 1, 2022.

- **Developmental Disabilities (DD) Councils Report Highlights:**
  - Sheraden Nicholau read the report from Vi Ibarra for Contra Costa County DD Council:
    - The Contra Costa Developmental Disabilities Council is working with the Contra Costa County Transition Task Force to offer an introductory Person-Centered Thinking presentation for families in Contra Costa County.
  - Gabby Romabiles gave a report for Alameda County DD Council:
    - 9 events and their dates were shared, and information and links were put in the chat. Three of the events were from Congreso Familiar for Spanish speaking families.
    - Alameda County Office of Education & Public Health Department is inviting Spanish speaking to hear from Dr. Noemi Spinazzi, from UCSF Children’s Hospital Oakland to talk about the COVID-19 vaccine for children aged 5-11. Link in chat
  - COVID-19 updates:
    - Alameda County Health Officials issued an order requiring providers engaging in 911 ambulance transport, non-emergency medical staff, and first responders like law enforcement and firefighters, to be fully vaccinated by December 21st, 2021. Unvaccinated individuals will need to wear masks in the presence of patients or residents and must test for COVID-19 weekly.
    - Alameda County is starting to ease masking requirements under certain conditions. See [Order 21-04](#)
8:35p Other Announcements:
- Sheraden Nicholau introduced Joe Hernandez from the State Council on Developmental Disabilities
  - Joe Hernandez shared his experience with the Self-Determination Program and a general plan on what he will be working on to help strengthen and perfect a statewide training. He also shared his background and experience.
- Elizabeth Grigsby: Invited RAC members to consider learning about Community Ready Corps and inviting them to a future RAC meeting for the purpose of beginning a collaboration. Sheraden shared a link in chat for their web page.
- Shawn Costello: Is the vice chair for the Human Services Commission; we had our meeting last month and Shawn chaired the meeting.
- Sheraden Nicholau: The next RAC meeting is February 23rd on Zoom. January 18th is the next State Council Legislative and Public Policy meeting on Zoom. The next Council meeting is on January 26th and the next advisory meeting is January 24th. February 10th is the next Employment First Meeting. February 15th is the next Statewide Self-Determination Advisory Committee Meeting.

8:50p Meeting Adjourned.
Bay Area Regional Advisory Committee  
c/o State Council on Developmental Disabilities Bay Area Regional Office  
1515 Clay Street, Ste. 803  
Oakland, CA 94612  

January 20, 2022  

State Council on Developmental Disabilities Legislative and Public Policy Committee  
c/o Bridget Kolakosky, Deputy Director, Policy and Public Affairs  
3831 N. Freeway Blvd. #125  
Sacramento, CA 95834  

RE. Limited Conservatorship Reform Feedback and Recommendations  

Legislative and Public Policy Committee Members,  

The Regional Advisory Committee (RAC) for the State Council’s Bay Area Region set out to review policy recommendations, gather community input, anecdotal evidence, and general feedback from the community on issues related to reform work needed in CA around limited conservatorship.\(^1\) This work was executed by a RAC member workgroup, with support from the State Council’s Regional Office.\(^2\)  

This RAC workgroup would like to elevate the following trends in observations and policy recommendations that have come from this work. Please consider these as you develop legislative advocacy work and focuses for the legislative cycle.  

**The Need for Data Tracking and Data Publication**  

The evaluation and reform of any system is dependent, first, on clear, consistently gathered and public data, coupled with anecdotal evidence including personal narratives. Californians report a lack of conservatorship-related data and data tracking available from counties in California, including the numbers of people in conservatorships, the status of those conservatorships, the numbers of petitions to the

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\(^1\) The workgroup reviewed policy papers, articles, op-eds, policy summaries, and testimony from US Senate hearings. Additionally, two community listening sessions were held, over Zoom, on December 20\(^{th}\) and hosted by RAC Chair and Co-Chair, Elizabeth Grigsby and Francisco Garcia. The community listening sessions were held in English with Spanish-Interpretation and English Captioning. Forty-six people attended the listening session, and 7 people provided emailed feedback.  

\(^2\) The Bay Area Regional Advisory Committee (RAC) Workgroup on Limited Conservatorship Reform was led by the following RAC members: Elizabeth Grigsby, John Marble, Pam Perls, and Marla Silversmith.
courts, the numbers of conservatorship terminations, the numbers of investigations, and the trends and challenges illuminated in that data.

- California should enact higher-standard data collection for better oversight and accountability.

- California should enact consistent and publicly available internal and system-wide audits to evaluate conservatorship implementation, performance, rights monitoring, and due-process.

Need for Person-Centered and Rights Focused Education and Monitoring

Person-centered and rights focused education, monitoring, and legal services require dedicated resources for personnel, processes, and audits. California is in need of these dedicated resources. People with disabilities, their family members, and advocates express that recently enacted AB 1194 does not address all of the advocacy and legal defense needs.

- All conservatees should be entitled to counsel, should they wish to challenge their conservatorship (also known as access to universal counsel). The State Bar should adopt attorney performance standards.

- Courts should enhance the wellbeing and safety of all adults who have court-appointed conservators by implementing a comprehensive, post-appointment person-centered monitoring system.

- As a part of this comprehensive, post-appointment person-centered monitoring system, California should dedicate the court monitoring and investigation personnel in each county to ensure conservators (including corporate/professional conservators) are doing their legal duty to always act in the best interests of the conservatee.

The Need to Elevate and Strengthen Alternatives to Conservatorship, such as Supported Decision Making

Many people with disabilities, their family members, advocates, and guardians are not knowledgeable about alternatives to conservatorship, and have not been given information on these alternatives. Additionally, many people with disabilities are not informed of their rights once in a conservatorship, including the process to seek termination of their conservatorship.
• California should provide comprehensive training, education, diversion programming, and outreach programs about alternatives to conservatorship, including Supported Decision Making and Person-Centered Planning.

• This training, education, diversion programming, and outreach programming should target both people with disabilities across life-stage, as well as family members and guardians. This programming needs to include plain language, and language / cultural competencies.

People with disabilities and their family members and advocates report times when they / their family member / their advocate has been locked out of decision making when facing a medical emergency or other type of crisis. Family members and advocates report feeling the need to seek out and/or maintain a conservatorship so that their highly involved loves one’s regional center and health care provider respect their loved one’s wishes, as enforced or advocated for by the conservator. Family members report that they do not trust the systems in place (e.g. Department of Developmental Services, Department of Social Services, regional centers, etc.) to properly respect and care for their highly involved loved one or to protect them / their loved one from fiscal abuse and other forms of abuse. This is especially a concern when people with disabilities and their family members or advocates look ahead to a time when the advocate is incapacitated or deceased and can no longer serve as an advocate.

Family members and advocates report that the fiscal burden of obtaining a conservatorship means that this option is often not feasible for low-income families and people with disabilities.

• California should enact laws that uphold patient and service recipient rights and advocate rights. This should include strengthening the power of Supported Decision Making and other alternatives.
  
  o For example, federal and state agencies could recognize that supported decision making be considered as a reasonable accommodation under the Americans with Disabilities Act.

• California should ensure that people with disabilities, their family members, and advocates have access to low and no-cost resources (e.g. conservatorships and alternatives to conservatorships) to ensure their / their loved one’s rights and wishes are respected and upheld in healthcare, financial services, and social service settings.
We would be pleased to provide any additional insight or information at the committee’s request. We urge you to address these pressing issues at this pivotal moment in our state and nation’s history when conservatorship reform and conservatee rights have been elevated to the forefront of public policy.

We would greatly appreciate your keeping our workgroup informed of what actions you pursue, so we can report back to our community.

Sincerely,

The Bay Area Regional Advisory Committee

Attachment:

Bay Area RAC’s Community Feedback / Listening Session Notes on Limited Conservatorship Reform December 2021

Further Reading and Resources:


Spectrum Institute (2022) The Route to Conservatorship Reform. Available at: https://spectruminstitute.org/2022/01/the-route-to-conservatorship-reform/.

UC Davis MIND Institute’s Supported Decision-Making Page and Resources. Available at: https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html.


Comité Asesor Regional del Área de la Bahía
c/o Oficina Regional del Área de la Bahía del Consejo Estatal de Discapacidades del Desarrollo
1515 Clay Street, Ste. 803
Oakland, CA 94612

20 de enero de 2022

Consejo Estatal sobre Discapacidades del Desarrollo Comité Legislativo y de Políticas Públicas
c/o Bridget Kolakosky, Directora Adjunta, Política y Asuntos Públicos
3831 N. Freeway Blvd. #125
Sacramento, CA 95834

RE. Comentarios y recomendaciones sobre la reforma de la tutela limitada

Miembros del Comité Legislativo y de Políticas Públicas,

El Comité Asesor Regional (RAC, por sus siglas en inglés) para la Región del Área de la Bahía del Consejo de Estado se dispuso a revisar las recomendaciones de políticas, recopilar aportes de la comunidad, evidencia anecdótica y comentarios generales de la comunidad sobre temas relacionados con el trabajo de reforma necesario en CA en torno a la tutela limitada.¹ Este trabajo fue ejecutado por un grupo de trabajo de miembros del RAC, con el apoyo de la Oficina Regional del Consejo de Estado.²

Este grupo de trabajo de RAC quisiera resaltar las siguientes tendencias en las observaciones y recomendaciones de políticas que han surgido de este trabajo. Considere esto a medida que desarrolla el trabajo de defensa legislativa y los enfoques para el ciclo legislativo.

La necesidad de seguimiento y publicación de datos

La evaluación y la reforma de cualquier sistema dependen, en primer lugar, de datos claros, recopilados de manera sistemática y públicos, junto con pruebas anecdóticas

¹ El grupo de trabajo revisó documentos de políticas, artículos, artículos de opinión, resúmenes de políticas y testimonios de las audiencias del Senado de EE. UU. Además, se llevaron a cabo dos sesiones de escucha comunitaria, a través de Zoom, el 20 de diciembre y fueron organizadas por la presidenta y copresidenta de RAC, Elizabeth Grigsby y Francisco García. Las sesiones de escucha comunitaria se llevaron a cabo en inglés con interpretación en español y subtítulos en inglés. Cuarenta y seis personas asistieron a la sesión de escucha y 7 personas enviaron comentarios por correo electrónico.

² El grupo de trabajo del Comité Asesor Regional (RAC) del Área de la Bahía sobre la reforma de la tutela limitada estuvo dirigido por los siguientes miembros del RAC: Elizabeth Grigsby, John Marble, Pam Perls y Marla Silversmith.
que incluyen relatos personales. Los californianos informan la falta de datos relacionados con la tutela y el seguimiento de datos disponibles de los condados de California, incluida la cantidad de personas en tutela, el estado de esas tutelas, la cantidad de peticiones a los tribunales, la cantidad de terminaciones de la tutela, la cantidad de investigaciones, y las tendencias y desafíos iluminados en esos datos.

- California debería promulgar una recopilación de datos de mayor nivel para una mejor supervisión y responsabilidad.

- California debe promulgar auditorías internas y de todo el sistema coherentes y disponibles públicamente para evaluar la implementación, el desempeño, el control de los derechos y el debido proceso de la tutela.

**Necesidad de Educación y Monitoreo Centrados en la Persona y Centrados en los Derechos**

La educación, el monitoreo y los servicios legales centrados en la persona y en los derechos requieren recursos dedicados para el personal, los procesos y las auditorías. California necesita estos recursos dedicados. Las personas con discapacidades, sus familiares y defensores expresan que la AB 1194 promulgada recientemente no aborda todas las necesidades de defensa legal y defensa.

- Todos los pupilos deben tener derecho a un abogado, en caso de que deseen impugnar su tutela (también conocido como acceso a un abogado universal). El Colegio de Abogados del Estado debe adoptar estándares de desempeño de abogados.

- Los tribunales deben mejorar el bienestar y la seguridad de todos los adultos que tienen tutores designados por el tribunal mediante la implementación de un sistema integral de seguimiento centrado en la persona después de la designación.

- Como parte de este sistema integral de monitoreo centrado en la persona posterior a la designación, California debe dedicar el personal de investigación y monitoreo de la corte en cada condado para garantizar que los conservador (incluidos los conservador corporativos/profesionales) cumplan con su deber legal de actuar siempre en el mejor interés del pupilo.

La necesidad de elevar y fortalecer las alternativas a la tutela, como la toma de decisiones con apoyo
Muchas personas con discapacidades, sus familiares, defensores y tutores no conocen las alternativas a la tutela y no han recibido información sobre estas alternativas. Además, a muchas personas con discapacidades no se les informa sobre sus derechos una vez que están en tutela, incluido el proceso para solicitar la terminación de su tutela.

- California debe brindar capacitación integral, educación, programas alternativos y programas de divulgación sobre alternativas a la tutela, incluida la toma de decisiones con apoyo y la planificación centrada en la persona.

- Esta capacitación, educación, programas de diversión y programas de extensión deben estar dirigidos tanto a las personas con discapacidades en todas las etapas de la vida como a los familiares y tutores. Esta programación debe incluir lenguaje sencillo y competencias lingúísticas/culturales.

Las personas con discapacidades y sus familiares y defensores informan momentos en los que ellos/su familiar/su defensor han sido excluidos de la toma de decisiones al enfrentar una emergencia médica u otro tipo de crisis. Los miembros de la familia y los defensores informan que sienten la necesidad de buscar y/o mantener una tutela para que sus seres queridos altamente involucrados, el centro regional y el proveedor de atención médica respeten los deseos de sus seres queridos, tal como los impone o defiende el tutor. Los miembros de la familia informan que no confían en los sistemas existentes (por ejemplo, Departamento de Servicios de Desarrollo, Departamento de Servicios Sociales, centros regionales, etc.) para respetar y cuidar adecuadamente a su ser querido altamente involucrado o para protegerlos a ellos/a sus seres queridos de abuso fiscal y otras formas de abuso. Esto es especialmente preocupante cuando las personas con discapacidades y sus familiares o defensores anticipan un momento en el que el defensor esté incapacitado o haya fallecido y ya no pueda desempeñarse como tal.

Los miembros de la familia y los defensores informan que la carga fiscal de obtener una tutela significa que esta opción a menudo no es factible para familias de bajos ingresos y personas con discapacidades.

- California debe promulgar leyes que defiendan los derechos de los pacientes y los beneficiarios de los servicios y los derechos de los defensores. Esto debería incluir el fortalecimiento del poder de la toma de decisiones con apoyo y otras alternativas.

  - Por ejemplo, las agencias federales y estatales podrían reconocer que la toma de decisiones con apoyo se considera una adaptación razonable en virtud de la Ley de Estadounidenses con Discapacidades.
California debe garantizar que las personas con discapacidades, sus familiares y defensores tengan acceso a recursos de bajo costo y sin costo (por ejemplo, tutelas y alternativas a las tutelas) para garantizar que sus derechos y deseos o los de sus seres queridos se respeten y se mantengan en la atención médica, los servicios financieros, y entornos de servicios sociales.

Estaremos encantados de proporcionar cualquier perspectiva o información adicional a petición del comité. Lo instamos a que aborde estos problemas apremiantes en este momento crucial en la historia de nuestro estado y nación, cuando la reforma de la tutela y los derechos de los pupilos se han elevado al frente de la política pública.

Le agradeceríamos mucho que mantenga informado a nuestro grupo de trabajo sobre las acciones que emprende, para que podamos informar a nuestra comunidad.

Atentamente,

El Comité Asesor Regional del Área de la Bahía

Adjunto archivo:
Comentarios de la comunidad del RAC del Área de la Bahía / Notas de la sesión de escucha sobre la reforma de la tutela limitada Diciembre de 2021

Further Reading and Resources:


Universidad de California, San Francisco, Office of Developmental Primary Care's Supported Healthcare Decision Making for Professionals. Disponible en:


Legislación del modelo de toma de decisiones con apoyo de Autistic Self-Advocacy Network. Disponible en:

Guía de atención médica para la transición a la edad adulta de Autistic Self-Advocacy Network para jóvenes y familias. Disponible en:


To: Regional Advisory Committee (RAC) Members & Interested Parties
From: Bay Area Regional Office
Re: 2021-2022 Schedule of Bay Area Regional Advisory Committee Meetings

Date: February 9, 2022

All Committee Meetings are open to the public. There is no physical location being made available to the public. Per EXECUTIVE ORDER N-29-20, teleconferencing restrictions are waived during the COVID-19 pandemic.

Networking from 6:15 pm to 6:30 pm and RAC Meetings are from 6:30 PM to 9:00 pm.

September 29, 2021
Community Outreach Meeting
Zoom link will be provided with the Agenda 10 business days before the meeting

December 1, 2021
Community Outreach Meeting
Zoom link will be provided with the Agenda 10 business days before the meeting

February 23, 2022
Community Outreach Meeting
Zoom link will be provided with the Agenda 10 business days before the meeting

April 27, 2022
Community Outreach Meeting Location TBD

June 29, 2022
Community Outreach Meeting Location TBD

July & August
No Meetings

Revised: 2/9/2022

"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."
Para: Miembros del Comité Asesor Regional (RAC) y partes interesadas
De: Oficina Regional del Área de la Bahía
Re: Calendario 2021-2022 de las reuniones del Comité Asesor Regional del Área de la Bahía

Fecha: 9 de Febrero de 2022

Todas las reuniones del comité están abiertas al público. No hay ninguna ubicación física disponible para el público. Según la ORDEN EJECUTIVA N-29-20, las restricciones de teleconferencia no se aplican durante la pandemia de COVID-19.

Networking de 6:15 pm a 6:30 pm y las reuniones del RAC son de 6:30 pm a 9:00 pm.

29 de Septiembre de 2021
Reunión de alcance comunitario
El enlace Zoom se proporcionará con la Agenda 10 días hábiles antes de la reunión.

1 de Diciembre de 2021
Reunión de alcance comunitario
El enlace Zoom se proporcionará con la Agenda 10 días hábiles antes de la reunión.

23 de Febrero de 2022
Reunión de alcance comunitario
El enlace Zoom se proporcionará con la Agenda 10 días hábiles antes de la reunión.

27 de Abril de 2022
Ubicación de la reunión de alcance comunitario TBD

29 de Junio de 2022
Ubicación de la reunión de alcance comunitario TBD

Julio y Agosto
No hay reuniones

Revisado: 2/9/2022

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