

Master Plan for Developmental Services Committee Meeting #9 -Summary Wednesday, December 11, 2024 9:00 a.m. - 3:30 p.m. Virtual Zoom Meeting

<u>Attendance</u>

Committee Members in Attendance

- Edith Arias
- Yvette Baptiste
- Sascha Bittner
- Claudia Center
- Shella Comin-DuMong
- Dora Contreras
- Lisa Cooley
- Brett Eisenberg
- Fernando Gomez
- Season Goodpasture
- Elizabeth Hassler
- Barry Jardini
- Mark Klaus
- Kelly Kulzer-Reyes
- Will Leiner
- Judy Mark
- Joyce McNair
- Mark Melanson
- Oscar Mercado
- Marty Omoto
- Joe Perales
- Eric Ramirez
- Norma Ramos
- Sara Speck
- Kavita Sreedhar
- Elena Tiffany

- Kecia Weller
- Amy Westling
- Gloria Wong
- Sylvia Yeh
- Larry Yin
- Brian Zotti

Facilitators and Presenters in Attendance

Catherine Blakemore, Karin Bloomer, Sandra Cross, Victor Duron, Jonah Frohlich, Katie Hornberger, Secretary Johnson Kim, Anna Lansky, Marlene Morales

Public in Attendance

Over 270 public attendees attended the meeting via Zoom video conference.

Pre-Meeting Presentation and Public Comment (Slides 5-15)

Victor Duron, Project Director, presented an overview of the master plan process and a recap of prior committee meetings. Victor also provided an overview of the five Master Plan workgroups and their priorities. This was followed by a premeeting public comment period. The comments received are summarized in the Public Comment summary document, which is available on the <u>Master Plan</u> <u>web page</u>.

Welcome (Slides 16-21)

Welcoming remarks, housekeeping, community agreements, and review of agenda.

Introductory Remarks from Secretary Kim Johnson

Victor introduced Kim Johnson, the newly appointed Secretary of the California Health and Human Services Agency. Secretary Johnson thanked everyone for their hard work on the Master Plan for Developmental Services. She talked about her own experiences with the system and said that she is dedicated to making a plan that includes everyone's voices. She was excited about the work ahead and stressed the need for everyone in California to work together to better meet the needs of people with developmental disabilities.

Review of Public Engagements and Input (Slide 22)

Victor Duron talked about the main ideas from recent community meetings including the Tribal Developmental Disabilities Symposium, the Deaf community, a group of service coordinators, and the Korean community. People said they want better communication and clearer information from regional centers, more transparency, easier-to-access services, more support and training for workers, and better help for families and individuals to find their way through the system. Many also mentioned the need for better housing and mental health services for people with disabilities. A document summarizing these community meetings is available <u>here</u>.

Workgroup Roundtable & Public Input Session Part 1 (Slides 23-32)

During the first session, committee members reviewed progress made in Workgroup 2.

At the last workgroup meeting, Workgroup 2 discussed their Universal Goal #2: Make life transitions easier, better and on-time. Workgroup 2 finalized 3 recommendations to improve life transitions:

- 1. At every life transition, people will get information, and if they choose a person-centered plan; and navigation supports, including peer supports.
- 2. High school students receive transitions supports starting at age 14. These include support to make their own decisions. This includes supported decision-making. It also seeks to reduce the number of initial conservatorships. People also develop their own career pathway. This includes competitive integrated employment (CIE) and post-secondary education.
- 3. Children who move from Early Start to schools and their families receive transition supports before the transition begins. This includes timely assessments by regional centers and schools. It makes sure that regional center fund services when there are no services and for after school hours.

Committee members were asked about their opinions on other big ideas for priority #2, including:

- Ideas for adults who are aging & want different kinds of services.
- Support for people with I/DD who are becoming parents.
- End of life planning.
- Ideas for people who enter the regional center system, at any age.

Feedback from committee members about these recommendations, big ideas, and other ideas included:

- Proactively plan for life transitions.
- Ensure continuous support and services through transitions.
- Address end of life planning for both individuals and caregivers.
- Standardize intake and assessment processes across regions.
- Coordinate family supports to ensure seamless care, especially for aging caregivers and those transitioning to independent living.
- Develop a roadmap for standardized systems and supports.
- Support and train parents of children with disabilities to navigate systemic challenges.
- Ensure legal protections and advocacy against biases in healthcare and child protective services.

- Offer co-housing communities and volunteer opportunities for aging adults with IDD to foster social connections and community engagement.
- Provide technology training at regional centers to help older adults stay connected with family and friends.
- Offer financial assistance programs to help individuals with IDD navigate social security, Medicare, and other support systems.

Break

Workgroup Roundtable & Public Input Session Part 2 (Slides 34-38)

During the second session, committee members reviewed the progress that Workgroup 3 has made.

Workgroup 3 has five draft recommendations for their priority #2 that they are working to refine. Priority #2 is: Provide competitive pay and employment supports to recruit and retain a high-quality workforce that includes people with developmental disabilities.

The recommendations are:

- 1. Create a State Leadership Academy to support employment for people with developmental disabilities to work in leadership positions at Regional Centers, State Departments, and the State Legislature.
- Create a State sponsored pooled benefits program that people in disability related careers, including people who are self-employed, could access if they do not receive these benefits through their employment. This could include healthcare benefits, retirement programs, and other savings and insurance programs.
- 3. Connect with the California Department of Education and launch a pilot program for middle and high school students, including students with disabilities, to explore and get exposure and work experience in disability services careers.
- 4. Create a State-sponsored study that will produce specific recommendations for types of financial incentives that could be provided to people in disability related careers. This could include tax breaks, loan forgiveness, and housing assistance.
- 5. To recruit people with developmental disabilities into the workforce, employers, particularly RCs and their vendors, should offer flexible benefits that complement their public benefits to meet their needs. This should include benefits planning and financial planning, particularly to support people who are new to employment.

Committee members were asked to provide their feedback on these recommendations and other ideas they have that can help address priority #2. Committee members' feedback included:

- Ensure the DD system workforce is enticing to join by offering long-term benefits.
- Continue and expand Stanford University's Rad Justice Project, which exposes law students to the DD community.
- Use technology and public media more effectively to promote DD services and community engagement.
- Strong support for the state leadership fellowship.
- Train employers on their responsibilities to individuals with IDD and labor laws.
- DOR should collaborate with DDS to create a comprehensive career or entrepreneurship pathway for self-advocates. This means a way for self-advocates to start their own new businesses.

Committee members were also asked to provide feedback on priority #3's problem statement and give ideas for draft recommendations.

Priority #3 is: Create clear roles and responsibilities for service coordinators to deliver culturally responsive, effective, and consistent services.

The draft problem statement is: Service coordinator roles are unclear and vary across Regional Centers. Their responsibilities vary and shift frequently. More training and supports are needed for service coordinators to understand how to best support individuals and families.

Committee members' feedback included:

- Define service coordinator roles and required training.
- Eliminate conflicts of interest for service coordinators serving both regional centers and clients.
- Define the terms "effective" and "consistent".
- Report progress on training and supports more frequently.
- Provide culturally responsive and effective training for service coordinators.
- Support and empower service coordinators when services are not readily available.
- Utilize technology to streamline processes and support service coordinators.
- Create a career ladder and promotional path for direct support professionals.
- Involve self-advocates in service coordinator training and curriculum development.

Lunch

Workgroup Roundtable & Public Input Session Part 3 (Slides 40-54)

Workgroup 4 (Slides 40-44)

Committee members discussed the progress made in Workgroup 4. Workgroup 4 asked for feedback about two recommendations:

- The first recommendation will focus on standardizing intake processes for Early Start and Lanterman populations as required in Senate Bill (SB) 138. Standardized intake processes are needed because individuals and families have very different experiences at different regional centers. There are no rules about when the process starts and stops. And individuals and families sometimes feel they don't have all the information they need about the intake process.
- 2. The second recommendation will focus on how the system will measure individual outcomes, system outcomes, and performance. The workgroup wants to develop a recommendation because there is incomplete information about individual and system outcome measures and performance. Survey and measurement efforts like the National Core Indicators (NCI-IDD) should be leveraged, but more data is needed. The recommendation is:
 - a. Develop a complete set of measures to identify and report on what works and what doesn't. Use measures to hold organizations accountable.
 - i. Measures can be used to link performance to payment.
 - ii. Measures can include surveys from individuals. All people would need to have equitable access to surveys and be able to respond to them.

Feedback from committee members included:

- Emphasize the importance of providing a positive, responsive, and human reception during the intake process.
- Address challenges such as families being turned away due to inadequate data tracking and communication issues.
- Standardize intake processes across regional centers to ensure consistent experiences and avoid delays.
- Train intake staff on cultural competence, sensitivity, and empathy to better support non-English speaking families.
- Provide transparency in eligibility decisions and clear explanations for denials.
- Offer short-term services during the waiting period for intake and eligibility, especially for those in crisis.
- Collect and use data to track and address disparities in access to services, including service denials and appeals.
- Ensure that surveys are accessible in multiple languages and culturally appropriate.

- Develop a system to evaluate the quality and outcomes of services provided, focusing on the individual's goals and needs.
- Improve communication between agencies to streamline processes and provide necessary services promptly.
- Protect families who speak out about issues from retaliation and ensure their feedback is taken seriously.
- Clarify the roles of the regional centers and the school systems to avoid confusion about responsibilities.
- Provide comprehensive information and support to families and individuals throughout the intake process.

Workgroup 5 (Slides 45-54)

Committee members discussed the progress made in Workgroup 5. Workgroup 5 is working on developing recommendations for their priority #2: Connect the different types of services that people with developmental disabilities use in California (Regional Center, schools, mental health, and more). This will help all the systems work together to help people live better lives and reach their goals.

At the last workgroup meeting, the workgroup discussed several recommendations including:

- Changing Medicaid authorities to make access to services easy.
- Making system navigation and service coordination better.
- Training for healthcare, behavioral health, and other professionals.
- Providing resources and creating flexible ways to pay providers.

Committee members were asked for feedback on other recommendations including:

- Preventing and eliminating discrimination.
- Creating healthcare that supports the whole person, which means their health and social needs, such as housing and job training.
- Developing Quality of life metrics.
- Doing a Gap Analysis, which is a study to identify what services individuals are not getting.

Feedback committee members gave on these 4 recommendations included:

- Include more plain language in advocacy and educational materials.
- Help individuals with IDD with personal care and daily tasks.
- Train medical professionals to better recognize disabilities, especially for individuals with low support needs.
- Create a parent-friendly environment in medical settings.
- Include the mental health of individuals with IDD in health care services.
- Increase the inclusion of individuals with IDD in waivers and state plans
- Further define the term "gap analysis".

- Ensure the systems that individuals with IDD use work together to create a more seamless experience.
- Make sure individuals with IDD know they are a protected class and can pursue anti-discrimination remedies.
- Ensure all needs are covered even if they are not directly a medical or health need.
- Avoid adverse selection. Adverse selection, in this case, means that doctors might prefer to treat patients who are easier to treat. This can mean that people who are harder to treat might have a harder time finding a doctor and might have to pay more for their care.
- Address the ableism bias that many health care providers hold.
- Include the term "intersectionality" in the recommendations.
- Create an ombudsman role for the Self Determination Program.
- Train more dentists to be capable of working with individuals with IDD.

Workgroup Roundtable & Public Input Session Part 4 (Slides 56-61)

Committee members discussed the progress made in Workgroup 1. Workgroup 1 is developing recommendations related to the Self-Determination Program (SDP).

A draft recommendation that all workgroup members support is: Require consistency and standards across the state at every regional center to ensure equity and participation in the SDP by requiring DDS to set up easy-to-follow processes for SDP participants statewide to: enroll, set individual budgets, develop spending plans, select services and supports, and use a Financial Management Service (FMS).

Committee members were asked to provide feedback on other ideas related to SDP, including:

- Breaking down barriers and making the SDP more consistent with more oversight.
- Ensuring every regional center client understands this option and is not discouraged from participating.
- Over time, significantly increasing participation in SDP so that it becomes the core of the system.

Feedback committee members provided about these ideas included:

- Service coordinators should receive enhanced training on SDP.
- Streamline the transition process between the traditional system and SDP.
- Increase the number of vendors and service providers within SDP.
- Standardize the process for spending plans across all FMS and regional centers.
- Improve the communication and responsiveness of FMS.

- Present SDP as an option to all new clients, but do not pressure or require people to enter SDP.
- Equally prioritize the traditional system and SDP.
- Embed the philosophy of self-determination at the core of the system.
- Provide participants with clear guidelines and support systems to navigate SDP effectively.
- Remove bureaucratic barriers to facilitate increased participation in SDP.

Public Comment (Slide 64)

At the end of the meeting, the workgroup co-chairs and facilitator supported a 30-minute public comment period. A summary of public comments is included in the Public Comment summary document which is available with other meeting documents are available on the <u>Master Plan web page</u>.

Meeting Materials:

• Discussion PowerPoint and other meeting documents are available on the <u>Master Plan web page</u>.