Attendance

Workgroup Members in Attendance

- Aderonke Adejuyigbe
- Alison Morantz
- Amy Westling
- Cheryl Whittle
- Domnique Mellion
- Dora Contreras
- Leticia ("Lety") Garcia
- Mark Melanson
- Tina Ewing-Wilson

Facilitators and Workgroup Chairs/Leads in Attendance

- Oscar Mercado (Co-Chair)
- Will Leiner (Co-Chair)
- Joe Perales (Equity Lead)
- Jonah Frohlich (Facilitator)

Public in Attendance

Over 90 public attendees attended the meeting via Zoom video conference.

Welcome and Introductions (slides 4-9)

After opening the meeting, Krystyne McComb, the Assistant Deputy Director of Communications at DDS, introduced the #FutureofCalDDServices photo campaign, encouraging participation and explaining how to join.

Discuss Priority 2 Recommendations (slides 11-26)

Equity Lead Joe Perales acknowledged difficulties some individuals have had when transferring between regional centers. He shared an update to the service authorization standards recommendation to include guidance for regional center transfers.

Priority Two includes recommendations to make it easy for everyone to get information they need and want. It also includes sharing information for research while keeping personal information private.

Workgroup members Alison Morantz and Tina Ewing-Wilson presented the **recommendation to increase access to high-quality data for individuals, the public, and researchers**. The recommendation included the following important points:

- People served by the system should be able to access their own data through a secure portal;
- The public should have access to more complete information on public websites;
- Researchers should be able to access data to evaluate how the system is performing;
- Privacy of individuals and their data must be maintained.

The recommendation also said we should create a system that tracks resources and measures outcomes, including personal goals and the experience of individuals and families.

The workgroup raised concerns about the risk of data breaches and the need to protect the privacy of individuals. The workgroup emphasized the importance of using information technology tools to keep the data researchers see separate from the data those making decisions about individual services see. The workgroup mentioned the need to follow data and technology best practices. Child welfare systems for example have done a lot to safeguard data security and privacy.

The group discussed the need for clear guidance on what information is being shared, for what purpose, and how it will be used. This transparency is important for gaining the trust of individuals and families. Workgroup members shared experiences and concerns about the lack of trust in regional centers and the need for better communication and legal protections to prevent unauthorized information sharing.

The workgroup continued with a discussion on the need for better data to measure the effectiveness of programs, identify disparities, and support accountability. The group said that robust stakeholder engagement was needed to identify equity measures and outcomes. They also discussed the importance of involving community members and researchers in the grant review process. This would help make sure that important community-based organizations had a greater opportunity to receive grant funding. It would also help make sure that grant applications can be evaluated using community-member input.

Break (10 minutes)

Discuss Other Priority 2 Ideas (slides 27-31)

The workgroup discussed other topics related to priority 2. The first idea emphasized the need for a single system to manage service access, delivery, and financing.

The workgroup highlighted the importance of this recommendation to improve accountability and transparency. While a lot of data is currently collected, many workgroup members felt it was not used well to inform policy or identify problems.

The workgroup agreed to write a recommendation for this idea and discuss it at the next meeting.

The next idea was about outcome measures. The workgroup said that there is incomplete information about individual and system outcomes. This makes it hard to create accountability and address disparities in the system. The workgroup said it was important to learn from existing surveys and measurement efforts, such as the National Core Indicators for Intellectual and Developmental Disabilities (NCI IDD) and Regional Center Performance Measures (RCPM). Learning about efforts would be helpful to develop a more comprehensive set of measures. The workgroup agreed to develop a recommendation related to this idea and discuss it at the next meeting.

Discuss Potential Recommendations for Intake Processes (slides 32-33)

The workgroup reviewed the idea of developing a standardized intake process. This is required by SB-138. The workgroup said a consistent intake process across regional centers was necessary to make sure equitable evaluations and eligibility decisions are made. The workgroup said that DDS is holding public input sessions to get community feedback on the design of this process. DDS shared questions that would be helpful for the workgroup's recommendation.

Workgroup members also shared personal experiences. They highlighted the need for a consistent intake process to ensure timely and equitable access to services. The workgroup stressed that evaluations should be comprehensive and should try to understand the unique circumstances of the individual to determine eligibility for regional center services.

The workgroup said that disparities in the intake process have been a long-standing issue. They emphasized the need for more complete data collection and reporting to hold regional centers accountable. One workgroup member pointed out that many families are turned away based on brief phone calls. A workgroup member said this should not be allowed. They suggested that the intake process should be described as a series of steps. And that each step should be tracked and reported to make sure a standard intake process is being followed.

The workgroup agreed to write a recommendation for this idea and discuss it at the next meeting.

Discuss Next Steps and Upcoming Meetings (slides 34-35)

Workgroup members volunteered to develop three new recommendations. The workgroup was also invited to submit ideas for priority #3. The Master Plan Team emailed a survey to collect their feedback before the next workgroup meeting on December 18.

Public Comment (slide 36)

A summary of public comments is included in the Public Comment summary document which is available with other meeting documents on the Master Plan web page (https://www.chhs.ca.gov/home/master-plan-for-developmental-services/).

Meeting Materials:

- Discussion PowerPoint and other meeting documents on the Master Plan committee workgroup web page (https://www.chhs.ca.gov/home/mpds-committee-workgroup/).