Master Plan for Developmental Services Workgroup 5 Meeting #6 Summary

Friday, January 17, 2025
10:30 a.m. – 1:30 p.m.
Virtual Zoom Meeting

Attendance

Workgroup Members in Attendance

- Joyce Cabrera
- Shella Comin-DuMong
- Katharine Hayward
- Barry Jardini
- Jay Kolvoord
- Hyun S. Park
- Viri Salgado
- Susan Stroebel
- Viri Salgado
- Isabel Torres

Facilitators and Workgroup Chairs/Leads in Attendance

- Elizabeth Hassler (Co-Chair)
- Anna Lansky (Facilitator)
- Kavita Sreedhar (Co-Chair)

Public in Attendance

Over 75 public attendees attended the meeting via Zoom video conference.

Welcome

Workgroup 5 Facilitator Anna Lansky and Workgroup 5 Co-Chairs Kavita Sreedhar and Elizabeth Hassler welcomed the workgroup members and members of the public to the meeting. Anna reviewed the agenda and community agreements to ensure a respectful and productive meeting.

Timeline for Creating Ideas and Recommendations (Slides 6-7)

Workgroup 5 Timeline (Slide 6)

The workgroup will meet continue to meet monthly to discuss and establish recommendations for each workgroup priority. Recommendations will be finalized in March and sent to the Master Plan Stakeholder Committee for consideration.

Developing Our Recommendations (Slide 7)

The workgroup will draft and revise a list of recommendations for each priority for the Master Plan Stakeholder Committee to review and approve. Workgroup member feedback and input can also be sent to the facilitators and co-chairs between meetings via email.

HCBS Gap Analysis (Slides 8-15)

Workgroup 5 Priority #2 (Slide 9)

The goal of the meeting was to discuss priority #2. Priority #2 is: integrate waiver and State Plan services across systems to improve quality of life and outcomes.

Why Gap Analysis recommendation? (Slide 10)

The workgroup is developing a gap analysis recommendation to find out what is working and what isn't working for people receiving services in the developmental disabilities system. This helps identify gaps in services and those who are left out, using accurate data. Conducting this process on a regular basis would ensure system improvements happen and help spot new problems.

HCBS Gap Analysis: update from DHCS (Slide 11)

Joseph Billingsley, Assistant Deputy Director at the Department of Health Care Services (DHCS), presented an update on the Medi-Cal Home and Community-Based Services (HCBS) gap analysis and multi-year roadmap initiative. His focus is on HCBS, including various waivers and programs under DHCS, and overseeing California Children's services programs.

Joseph began by explaining the origins of the initiative, which stemmed from a "Money Follows the Person" demonstration grant awarded in 2020. This grant, first introduced by CMS in 2007, aims to help states transition individuals from institutional settings to community-based care. California has been a grantee since the program started.

In 2020, CMS released a capacity-building initiative to accelerate long-term services and support system transformation. California received $5 million in supplemental funding to conduct a gap analysis of Medi-Cal HCBS. The Center for Health Care Strategies, subcontracted by Mathematica, led the stakeholder engagement for this project.

The gap analysis aims to identify and close gaps in access to HCBS, develop strategies for better integration, and improve health outcomes, member satisfaction, and health equity. The work began in 2023, involving data collection from various departments. Mathematica created a gap analysis report in September 2023 to be reviewed by internal and external stakeholders. The final report will be released in February 2025.

Joseph also discussed the development of a multi-year roadmap, set to be released in summer 2025. This roadmap will guide the integration of applicable waivers into California's managed long-term services and supports delivery system.

Joseph emphasized the importance of stakeholder engagement, including public meetings and committee discussions. The gap analysis includes programs like MSSP, HCBA, ALW, IHSS, and CCT, while excluding programs for individuals with intellectual and developmental disabilities (I/DD) and the HIV/AIDS waiver.

During the workgroup Q&A, Joseph discussed various topics with workgroup members including:

- The need for a gap analysis for developmental services.
- Extending elderly services like PACE to people with I/DD.
- The involvement of individuals with I/DD in surveys. Joseph clarified that the HCBA waiver is administered by DHCS and serves a broad range of individuals, including those with I/DD. HCBS is one of the waivers recommended for integration into Managed Care.
- Challenges of data acquisition and the need for better data collection and sharing practices.
- Workgroup members expressed that I/DD wavers and services should not be considered for integration into Managed Care. Any gap analysis for I/DD system should not have that as a goal.
- Concerns about the presentation being too technical for most people to understand and the potential for bureaucratic delays. Joseph acknowledged the need for plain language presentations and better coordination across systems going forward.

Priority 2, Recommendation 8: Gap Analysis (Slides 12-15)

Anna reviewed the next recommendation with the workgroup, which directly related to the information Joseph provided to the workgroup.

Recommendation 8 is:

- We recommend a study of the ways people with developmental disabilities are served in systems across California. This is called a gap analysis.
- A gap analysis is a way to make sure that we know the ways the system is and isn't working, so that it is easier to fix or change it.
- The recommendation was originally for the gap analysis to be specifically of Medicaid.

- This was to make sure that Medi-Cal and related systems (like In-Home Supportive Services (IHSS)) are being looked at to make sure they make changes to better serve people with developmental disabilities.
- It is also important to look at other systems people use in the state that are not Medi-Cal or the Regional Center (like the foster care system, schools, and the justice system).
- This is to make sure we know all the ways people with developmental disabilities need to be supported in those systems and all the different funding types that might help us get there.
- If people need support in learning how to work with people with developmental disabilities, Regional Centers should play an important role. This is sometimes called "technical assistance."
- There also needs to be a big conversation across systems about the needs people have and where they currently are and aren't being met. This information will help make sure technical assistance can happen and work well.
- It can also help us better support people from different cultures, who speak different languages, and more.
- We are trying to make sure that everybody who works in different state systems works together to support people with developmental disabilities, because this is important to help California thrive.
- As part of the gap analysis, review the Lanterman Act to:
  - List all services that people with intellectual and developmental disabilities (I/DD) should get.
  - Find out who pays for each service and which agency is in charge of it.
  - Make sure people with I/DD can actually get all the services they need and have a right to.

Workgroup members discussed the importance of clear and specific language in this recommendation. The workgroup discussed the ambiguity of the term "generic" and suggested that a clear definition from the Department would prevent varied interpretations across regional centers. It was stressed that the Lanterman Act ensures that conditions do not get worse and that services should not be denied while payment responsibilities are determined.

A proposal was made to add language to the last bullet point on slide 15 to address timeliness and seamlessness, ensuring that the burden of navigation does not fall on parents or individuals. This was agreed to, noting that it complements a previous recommendation about reducing the system navigation burden placed on families.

Updates on Overlap with Other Workgroups (Slides 16-17)

Anna noted the following workgroup 5 recommendations have been referred to other workgroups to be completed:

- The recommendation on improving ways people find out about DD services and regional centers has been referred to workgroup 1.
- Priority #2 Recommendation #7 – “Quality of Life Metrics” has been referred to workgroup 4.
- The idea about developing a community resources database has been referred to workgroup 2.
- The idea to develop peer supports has been referred to workgroup 1.

Workgroup members talked about how to make sure recommendations sent to other workgroups are properly handled. One member was worried that these recommendations might not be clearly understood or included. They suggested creating a feedback system to track this.

Another member said that when other workgroups' recommendations come in, they can be shared on the shared Teams site for feedback. They also offered to help anyone interested in specific recommendations. It was suggested to map out which workgroup is handling each recommendation in a transparent way.

Updates to Priority 1 Recommendation (Slide 18)

Anna noted that Workgroup 5 will add the following language to Priority #1 Recommendation #1: *“Explore options for raising income limits above current levels to allow more people to be Medicaid eligible, including through the working disabled program.”*

Priority 3 Draft Recommendation (Slides 19-26)

Workgroup 5, Priority #3 (slide 19)

Anna reviewed workgroup 5, Priority 3 which is: *Innovate and expand person-centered and culturally informed service types that support community living and can be covered by Medicaid or other systems, such as housing or transportation, to promote inclusive systems and communities.*

Workgroup 5, Priority #3 Universal Goal (slide 20)

Anna reviewed the universal goal which is: Californians with intellectual and developmental disabilities get innovative, person-centered, and culturally informed services from all systems, community organizations, and their communities. This supports people with I/DD to live in their community how they want. Systems and services are well funded by Medicaid or other programs and funding sources.

Workgroup members discussed the importance of community preferences, emphasizing that care should not be institutionalized or overly restrictive and be suited to the individual's preferences. They agreed that maximizing self-direction and inclusion should be priorities. It was noted that supporting people with I/DD to live self-determined lives in the community, with the supports they need, is crucial.

There was a discussion about specifying funding sources, with suggestions to include Medicaid, Medicare, and other potential funding sources. It was proposed to use broad terms in the recommendation such as "federal, state, and other funding sources" to cover all possibilities, including private foundation grants.

The group agreed to add language emphasizing lifelong support, self-determined lives, and various funding sources. They also discussed the terminology around self-direction, deciding to use lowercase "s" and "d" as previously described to differentiate between the "Self Determination Program" and self-determination as a general concept.

Workgroup 5, Priority #3 Problem Statement (slides 21-24)

Anna reviewed the problem statement for Workgroup 5, Priority #3. The problem statement is:

- Some important services and supports, like help with affordable housing, are not enough for all people who need them. It is even harder for people with I/DD to receive those services.
- California is facing an affordable housing crisis as home values and rents have become among the highest in the nation. The affordable housing crisis disproportionately impacts people with IDD as the vast majority live on fixed incomes that are at or near poverty level thresholds.
- When people with I/DD are excluded or have a hard time getting services and supports from other systems or organizations that are supposed to serve them, I/DD system has to fill in the gap or provide more costly services. These services may not be eligible for Medicaid/federal match. This can impact DDS budget.
- Students with I/DD are not provided equitable opportunities to be fully included in educational process. Special Education system needs an overhaul.
- Some services and supports can still make it harder for people with IDD to be included in the community or make their own choices. These service models can feel like old-style institutions.

- More innovative models are needed that do not put people with I/DD into separate places where they can only be with other people with disabilities and paid staff.
- Students with complex needs do not get access to meaningful education opportunities with needed supports. This leads to lack of opportunities later in life, like employment. Lack of access to equitable education sets trajectory for the rest of person's life.

Workgroup members discussed the challenges people with I/DD face in accessing affordable housing. It was noted that there are not enough resources to support everyone, and high home rents disproportionately impact people with I/DD, who often live on fixed incomes and face credit record challenges. Caregivers who earn low wages also struggle in the housing market. The discussion highlighted various barriers and suggested focusing on specific components to address these issues.

It was mentioned that when people with I/DD are excluded from housing access services or struggle to get the supports they need, they risk being placed in more restrictive settings. This point could be used to access more federal resources, especially for those identified as at risk of institutionalization. There was also a call for better data collection to understand the problem better.

One workgroup member suggested rewording the statement to be more active, emphasizing that people with I/DD are excluded from housing. They noted issues like price gouging and the need for a nimble system to support those who are inadequately housed. It was acknowledged that this is an ongoing issue.

Another member pointed out that integrated settings lead to better outcomes for kids compared to segregated ones, advocating for universal design. The lack of mention of transportation in the problem statement was also raised, highlighting the importance of timely and safe transportation for people with I/DD. Examples included planning rides 24 hours in advance and access to drivers, vehicles, and rideshare services.

Priority #3 Draft Recommendation #1: Supported Living Services (SLS) (slide 26)

The workgroup reviewed priority 3, draft recommendation 1:

- Develop enough providers of SLS so that people do not have to wait to receive it.
- Create ways to make sure services are high quality, person-centered, and culturally informed.
- Develop a way to make sure that SLS is following Home and Community Based Settings rule requirements (HCBS rule), even though SLS settings are person's own homes and presumed to be HCBS compliant.

- DDS should consider using a client Advisory Council or another method to identify, review, and resolve problems.
- Make SLS services available to people living with family.

Workgroup members discussed the challenges of hiring and finding staff, emphasizing the importance of building for staff capacity. They highlighted that Supported Living Services (SLS) should enable people to live in their own communities, near family and friends, and not be dependent on waivers.

It was noted that many adults receiving regional center services live with aging caregivers who may no longer be able to provide the necessary support. SLS needs to be as visible as supported and independent living services. Making SLS available to those living with family was deemed crucial, along with having a succession plan for service coordination.

There was a discussion about past regulations that made SLS inaccessible to individuals living at home, and the need to remove such barriers. The importance of considering cultural contexts, where families prefer to care for their loved ones at home, was also highlighted.

The group talked about developing enough providers, which could involve state efforts, streamlining processes, and reaching out to community organizations. There was a call for clear definitions of SLS for families and individuals, and for more transparency between SLS agencies and service recipients to ensure accurate billing and reporting of discrepancies.

The Workgroup did not have time to review all remaining draft recommendations 7 during the meeting. Members will have opportunities to share their thoughts with the facilitator and co-chairs before the next meeting in February.

Public Comment (Slide 52)

At the end of the meeting, the workgroup co-chairs and facilitator supported a 30-minute public comment period. A summary of public comments are included in the Public Comment summary document which is available with other meeting documents on the [Master Plan website (https://www.chhs.ca.gov/home/master-plan-for-developmental-services/)](https://www.chhs.ca.gov/home/master-plan-for-developmental-services/)

Meeting Materials:

- Discussion PowerPoint and other meeting documents can be found on the [Master Plan website (https://www.chhs.ca.gov/home/master-plan-for-developmental-services/)](https://www.chhs.ca.gov/home/master-plan-for-developmental-services/)