Master Plan for Developmental Services Workgroup 5 Meeting #5 - Summary

Friday, December 6, 2024

11:30 a.m. – 2:30 p.m.

Virtual Zoom Meeting

Attendance

Workgroup Members in Attendance

- Shella Comin-DuMong
- Cindy Cox
- Barry Jardini
- Mark Klaus
- Jay Kolvoord
- Hyun Park S.
- Olivia Raynor
- Viri Salgado
- Susan Stroebel

Facilitators and Workgroup Chairs/Leads in Attendance

- Elizabeth Hassler (Co-Chair)
- Mark Klaus (Equity Lead)
- Anna Lansky (Facilitator)
- Kavita Sreedhar (Co-Chair)

Public in Attendance

Over 61 public attendees attended the meeting via Zoom video conference.

Welcome and Self Introductions

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. They thanked everyone for their willingness to participate and engage in this work. Anna reviewed the Community Agreements to ensure a respectful and productive meeting.

Timeline and Process for Creating Ideas and Recommendations (Slides 6-8)

Workgroup 5 Timeline (Slide 6)

The workgroup will meet once per month over the next 4 months 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.

HCBS Gap Analysis (Slide 7)

Anna explained that representatives from CalHHS would be joining the January meeting to review the gap analysis instead of discussing this during this meeting.

Developing Our Recommendations (Slide 8)

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.

Workgroup 5 Priority #2 Draft Recommendations (slides 9-31)

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.

Summary of Draft Recommendations (Slide 10)

Anna reviewed the summary of draft recommendations for Priority #2. These recommendations include:

1. Changing Medicaid authorities to make access to services easy
2. Make system navigation and service coordination better
3. Prevent and eliminate discrimination
4. Training for healthcare, behavioral health, and other professionals
5. Providing resources and creating flexible ways to pay providers
6. Creating healthcare that supports the whole person
7. Quality of life metrics
8. Gap Analysis

Priority 2, Recommendation 1: Medicaid Authorities (Slides 11-12)

Anna reviewed the first draft recommendation for priority #2 and explained that the term “Medicaid Authorities” refers to the way CMS approves the ways that states pay for services. Workgroup 5 wants to structure those authorities in a way that promotes access to services.

Recommendation 1 is:

- DHCS needs to structure Medicaid authorities (such as Waivers and state plan options) in a way that creates seamless and easy access to services and supports.
- Regional Centers will support individuals and families in understanding and navigating available options.
- DHCS and DDS will work with individuals with I/DD, family members, and community partners to do a review of Medicaid authorities to identify barriers and services gaps and identify options for integrating Medicaid authorities into a seamless program.
- In collaboration with individuals with I/DD, family members and community partners, develop and implement Medicaid authorities alignment strategy to remove barriers and service gaps and build a seamless system of life-long support. (Option to add specific completion timeline that DDS and DHCS can be held accountable to)

The workgroup discussed many ideas about changing recommendation 1. First, they said that Priority 2's goal is to use state plan and waiver money to bring together the different systems that people with I/DD use in California. The second bullet point should include phrases like "regional centers will continue" or "regional centers will enhance" to show that some regional centers are already helping people understand the services available. They also mentioned that this recommendation will need new educational materials for service coordinators, so they have all the information needed to help people and families in the best way.

<u>Priority 2, Recommendation 2: Medicaid Authorities (Slides 13-16)</u>

Anna reviewed the second draft recommendation for priority #2. Recommendation 2 is:

- Systems support individuals and families with robust coordination and navigation of services they provide.
- Systems also connect and coordinate with each other to ensure holistic and seamless approach to supports.
    - Establish formal agreements between Managed Care organizations, Regional Centers, and Counties to:
        - Define roles and responsibilities for coordination and navigation of services.
        - Create processes and practices for coordination of supports across systems using person-centered principles and practices. This includes sharing of data and information.
    - Make Enhanced Care Management (ECM) available through Medi-Cal to individuals with I/DD.

    - Make ECM part of formal agreements and ensure ECM coordinates with Regional Centers and County BH programs.
    - Clearly distinguish ECM from service coordination provided by Regional Centers.
  - For individuals with complex cross-system needs, require systems to work together as a multi-disciplinary team to support individuals using a whole person approach.
  - Ensure systems recognize that individuals with I/DD can have a full range of human experiences, including physical health, mental health and substance use conditions.
  - People with I/DD are entitled to receive necessary services and supports to meet all their needs.
  - Systems need to stop using concept of "primary diagnosis" to deny or limit access to needed supports.
  - Develop and implement accountability and performance metrics which provide information on how well the systems are doing in supporting navigation, coordination, and communication. Establish incentives and enforcement approaches.
  - Establish a more efficient communication system between the regional centers, service providers, and individuals and families. Communication needs to be supported in the language preferred by the individual and their family and should be in plain language.

Workgroup members talked about making sure families don't need to work with many different agencies to get the care they need and are entitled to receive. They said this recommendation helps those already connected to regional centers, but not everyone eligible for services knows about regional centers. Schools, doctors, and community organizations could do more to inform people about I/DD services with additional education and resources. They agreed there should be easy-to-find information about services and eligibility for families. The workgroup also said navigation supports should be ongoing and referral sources should be tracked to better understand how people enter the system.

The workgroup also talked about problems like not having enough workers at regional centers and doctors not knowing how to work with people with I/DD. The recommendation should explain what "efficient communication system" means and include a survey after any interaction to check performance. Some members suggested making an app like MyChart for communication and follow-up, but others said many people in rural areas may not have internet connectivity to allow them to use some of these tools. Anna said other groups are working on technology and data too.

Priority 2, Recommendation 3: Preventing and Eliminating Discrimination (Slides 17-21)

Anna emphasized that disability, including I/DD, is a protected class according to federal law. A protected class is a group of people who are legally protected from discrimination based on a shared characteristic. Anna also mentioned that the National Institutes of Health (NIH) designated people with disabilities as a population with health disparities in 2023 in part due to discrimination, inequality, and exclusionary practices that limit access to healthcare.

Recommendation 3 is:

- Implement efforts to prevent and eliminate discrimination against individuals with I/DD.
    - Disability, including I/DD, is a protected class under ADA, and individuals with I/DD are protected under ADA and other federal statutes and rules including Section 504 of the Rehabilitation Act and Section 1557 of the Affordable Care Act.
    - Full inclusion in community life is not possible while discrimination and segregation persist within service systems and communities.
- State Plan services: DHCS needs to proactively implement non-discrimination within healthcare and behavioral health systems the agency funds and regulates.
    - Expectations around compliance need to be made explicit with measurements, accountability, and enforcement mechanisms in contracts with Managed Care Organizations, Counties, Regional Centers, providers, and other system's partners.
- DHCS needs to provide support on transition to compliance, including:
    - Provide targeted outreach and education, including information about providing accommodations to individuals with I/DD.
    - Provide technical assistance, training, and outreach to help professionals and organizations understand their rights, responsibilities, and mandates to serve individuals with I/DD.
- DHCS must engage self-advocates, family members, DDS and I/DD community partners in developing and implementing strategies and accountability measures to achieve full compliance with antidiscrimination laws and rules.
- DHCS must develop and regularly report on data and measures specific to disparities, access, and utilization for people with I/DD compared to population without disabilities. Data must be broken out by race, ethnicity, gender, language and other demographic characteristics.
- DHCS must regularly report on status of Final Rules implementation (Final Rule implementing Section 504 of the Rehabilitation Act and Final Rule implementing the anti-discrimination provisions under Section 1557 of the Affordable Care Act).

Workgroup members shared that services are often not given because service providers say they not a "good fit." They want to track these cases to understand why someone didn't get help and to find ways to fix it. Some members suggested using technology to report unfair treatment and problems faced by people with disabilities. They stressed the importance of being sensitive about cultural, geographical, and cost issues. They mentioned problems in rural areas and worries about ADA rules and funding. They believe there should be more help for the IDD community in these places, including better ways to reach them.

The workgroup agreed that there needs to be a faster response to reported discrimination. They proposed creating training programs by people who receive services for the professionals in order to better support the community. They also suggested discussing how adverse selection might play a role in providers unfairly choosing not to provide services for people with disabilities.

Priority 2, Recommendation 4: Training Professionals (Slides 22-23)

The workgroup reviewed recommendation 4:

- Healthcare and behavioral health workforce development must be based on universal design principles for healthcare and behavioral health systems that are competent to serve everyone, including individuals with I/DD.
- Implement systemic change and requirements for educational and credentialing systems (e.g. medical schools) to incorporate learning about disability as a natural part of human experience in educational programs for healthcare, BH, educational, and other professionals.
- Incorporate requirements for training on person-centered principles and practices into healthcare and BH workforce development.
- Ensure systems and professionals are aware of their legal obligation to serve all individuals regardless of the disability status and provide necessary accommodations to ensure equitable services for individuals with ID/DD.
- Establish awareness building and education efforts about disability for general community.

Workgroup members said we should add more support for training for short-term help with mental health providers, substance use providers, police, lawyers, and child welfare workers. They also said we need more dentists who are trained to treat adults with disabilities. Training should be provided to help individuals use their support staff to make their own choices. The workgroup facilitator is going to meet with the facilitators of Workgroups 2 and 3 to verify that they are working on these recommendations. They also discussed the importance of making transportation affordable and accessible for individuals receiving services.

Priority 2, Recommendation 5: Resourcing the Systems (Slides 24-26)

The workgroup reviewed recommendation 5:

- Provide adequate resources to ensure there are enough providers for people to choose from across the state. This includes providers within I/DD system, healthcare system, and behavioral health system.
    - DHCS and DDS must hold Managed Care Organizations and Regional Centers accountable to ensure adequate provider networks across the state and timely access to services.
    - Develop and regularly report on measures related to provider availability across the state, including linguistical and culturally specific capacity.
- Develop flexible funding models for I/DD, healthcare and behavioral health providers that ensure access, availability of disability related accommodations and accessibility supports to people with I/DD, as well as allow individuals to be served in a culturally appropriate and person-centered way.
    - Services across I/DD, healthcare, and behavioral health systems should be adequately resourced to provide individualized supports, allow providers to collaborate effectively, and implement innovative solutions that could improve quality of life outcomes.
- To prevent adverse selection (providers only serving individuals with fewer support needs), funding models for I/DD, healthcare, and behavioral health providers must reflect level of need of individuals and cost of services that meet their needs.

Workgroup members shared that regional centers don't control state money and can't decide on resources by themselves. So, the first point should instead say that DDS and the state are responsible for providing enough resources to Regional Centers to do provider development. They highlighted that having enough money is key to having good provider networks. Members suggested organizations need to be notified earlier when funding opportunities become available because many don't know until it's too late to apply. Some members said the system should use its funding and not send it back to the state; it could be used for special projects. Others were worried that this might make regional centers or the state not spend money on necessary services. Workgroup members stated that the process for getting vendorized as a service provider is really complicated and takes a lot of time.

Providers need to get multiple credentials or certifications from different departments, which makes it hard and discourages them from offering their services. Workgroup members suggested incentivizing the paperwork that providers need to complete to work with individuals with disabilities. Workgroup members also recommended that affordable housing systems should also be resourced properly.

Priority 2, Recommendation 6 (Slide 27)

The workgroup reviewed recommendation 6:

- Develop equitable medical and behavioral health care where all aspects of an individual's health are addressed and not overlooked because they have a disability. This will lead to healthier individuals with disabilities living a better quality of life.

Workgroup members noted that this idea should be its own recommendation. Like in recommendation 5, housing needs to be addressed.

The Workgroup did not have time to review recommendations 7 and 8 during the meeting. Members will share their thoughts with the facilitator and co-chairs before the next meeting in January.

Next Steps: Priority 3 Homework Survey (Slides 32-35)

Anna reviewed the next steps for developing recommendations for Priority 3, including a homework assignment that will be sent out to workgroup members after the meeting to submit their ideas related to priority 3.

Upcoming Workgroup Meetings and DDS Photo Campaign (Slides 36-41)

Before moving to public comment, Anna reviewed the dates of the upcoming Workgroup 5 meetings. Krystyne McComb, DDS Assistant Deputy Director of Communication, presented the Future of DDS photo campaign to the workgroup. She asked workgroup members and the public to take photos of themselves holding up signs that describe what the future of developmental services is to them. Individuals should submit their photos and consent forms to **pio@dds.ca.gov** or on the DDS website at https://www.dds.ca.gov/the-future-of-developmental-services/.

Public Comment (Slide 42)

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/).

Meeting Materials:

- Discussion PowerPoint and other meeting documents: (https://www.chhs.ca.gov/home/master-plan-for-developmental-services/).