

Overview of Master Plan Community Engagements

Community engagements since the August 21st Master Plan Committee Meeting overview:

HOST	COMMUNITY	DATE
Westside Resource and Empowerment Center	Ethiopian parents, family members, and people with developmental disabilities.	8/16/2024
DVU Communication Access Connect	Augmented and Alternative Communication (ACC) users and their families.	8/20/2024
El Arc de California	Committee members of El Arc representing the Latino community	9/03/2024
State Alliance Team for Aging	Representatives of state and local entities serving older adults and people with disabilities	9/04/2024

WREC – Ethiopian Parent Support Group

- Families feel regional center staff do not have the tools or training, including equity tools and training, needed to serve all individuals and families that need services.
- The Master Plan should consider that in many cultures, people see service providers as authorities. They don't feel comfortable speaking up for themselves in the ways required to receive services in this system today.
- Families need more support and peer groups to learn from others who have gone through the same things and can help us know what to expect.
- Families need to get information about services earlier so they can prepare and apply in time to actually receive them when we need them. Currently families are under pressure to be experts in DD services, or even service providers themselves, to make sure their child receives the services they need.
- Families need one place where they can find information from many service providers. The providers should be checked for quality, consistent standards, and everyone should get the same clear information.
- The Master Plan should consider that it is difficult to find other types of services that are not I/DD specific but meet the needs of people with I/DD, like dentists, housing, and behavioral health.
- The Master Plan should consider that there is a big drop-off in available services for adults older than school-aged.

DVU Communication Access Connect

- The Master Plan should work to improve communication and communication access across services like law enforcement, education, and mental health, especially for those with the most significant behavioral needs.

- There are long waitlists for services, delays between service approval and access, and inconsistent support from Regional Centers making it hard to get the help that is needed at the time when it is needed.
- There is not a consistent experience for individuals and families between Regional Centers and lack of consistency across Regional Centers on their directives.
- Finding dentists, especially for those needing sedation, is difficult, with long wait times and limited options.
- Once children age out of the school system, accessing adult services becomes a huge challenge.
- People with disabilities can struggle to access services because they're seen as "too high functioning", but this determination is subjective and inconsistent.
- There is no centralized system for services, making it confusing and hard to navigate multiple departments such as Public Health, Medi-Cal, Health Services and DDS.
- Even when communication devices are made available, supports and training for using them are often inadequate, making people feel silenced.
- The system forces families to prove they need services repeatedly, leading to frustration and distrust.

El Arc de California

- Workgroup 5 should consider how to focus on the Lanterman Act when forming its recommendations.
- Services are inconsistent across regional centers. There should be a minimum set of services that everyone is entitled to, and the eligibility process should be the same at all regional centers.
- The Master Plan should consider recommending the creation of a unified system where all regional centers provide the same information, menu of services, and eligibility processes, in multiple languages.
- Regional centers should be held accountable for poor performance and there should be clear and visible penalties for denying services without good reason.
- People need better support when services are denied, including help finding alternatives. DDS should report on what services are being denied across the system for transparency.
- FMS needs to be strengthened because a lack of FMS is a major barrier to SDP, including contracting, adequate rates, and timely pay.
- The Master Plan should work to make sure more diverse voices from different communities, including Latino communities, are included in planning discussions.
- Language access is a big issue, and it's not just about translation—people need to understand how the system works and be trained to advocate for themselves.

- Families want to know why some funds are returned instead of being used to improve services.
- The process to become a service provider (vendorization) is very complicated and makes it difficult to establish services in high need areas, especially for smaller providers.
- Regional Centers should be rewarded for good performance and penalized for poor performance. If DDS cannot oversee regional centers, the community needs another system to do it.
- Independent third-party reviewers should look at self-determination plans to ensure fairness and accountability.
- Trust is a big issue, and it's easy to lose faith in the system when services aren't delivered or are hard to access.

State Alliance Team for Aging

- There's a lack of information about how to support people with disabilities in the transition to older adulthood. Schools that train people to work with older adults should include specific training on disabilities and aging.
- Families, especially from minority backgrounds, need better support and navigation help to prepare for long-term needs. This includes more legal resources and having navigators who understand both aging and disability.
- Service coordinators are overwhelmed and may not have expertise in all age groups. Splitting them into teams based on age (like early childhood, youth, adulthood, and aging) might help.
- Services for aging people with disabilities should consider both medical and social needs, including community-based living and social isolation.
- Coordinated Family Supports (CFS) is a great start, but the Master Plan should consider expanding on it and offering more education about what CFS offers.
- There should be clear plans for who makes decisions and takes responsibility if a primary caregiver can no longer help. This is crucial for people with language barriers and those in the self-determination program.
- Senior centers should be welcoming and accessible to people with disabilities. We need to make these spaces inclusive and ensure that they meet the needs of older adults with disabilities.
- The Master Plan should explore recommendations for supporting pilots for housing options like shared housing where individuals with spare rooms can benefit others in need.
- Senior centers and other spaces for older adults should adopt universal design principles to be more inclusive to people of all abilities.

Community Engagements for Future Report Outs

- Golden Gate Regional Center Advocates Group
- “Chai, Coffee, and I” with South Asian families
- Voices for Change Forum with East Asian families
- State Council on Developmental Disabilities
- Tribal Developmental Disabilities Symposium
- Convening with Rural NorCal Communities
- Focus Groups series with Service Coordinators
- Korean Families Support Group