

Overview of Master Plan Community Engagements

Community engagements since the June 5th Master Plan Committee Meeting:

HOST	COMMUNITY	DATE
DDS Hispanic/Latino Focus Group	Hispanic/Latino advocates that meet regularly with DDS to provide input.	6/7/2024
CA Foundation for Independent Living Centers	Directors and senior leaders of California's Independent Living Centers.	6/13/2024
Association of Regional Center Agencies	Regional Center Executive Directors.	6/20/2024
DDS African American Focus Group	African American advocates that meet regularly with DDS to provide input.	6/28/2024
Integrated Community Collaborative	Hispanic/Latino Spanish speaking families and self-advocates.	7/11/2024
Service Access & Equity Monthly Meeting	Representatives of DDS's Service Access & Equity grant recipients.	7/12/2024
Family Resource Centers Network of California	Directors and senior leaders of California's Family Resource Centers.	7/17/2024
Summer Institute on Neuro-developmental Disabilities	Families, self-advocates, & professionals attending MIND institute conference.	7/19/2024

DDS Hispanic/Latino Focus Group

- There is a need for representation from diverse experts and groups, including from within the diverse Hispanic/Latino communities, to ensure that a wide range of perspectives and expertise is considered in the development of the master plan.
- Urged that there be more representation from the Hispanic/Latino community on the committee and workgroups developing the Master Plan.
- Stressed the importance of including self-advocates, family members, service providers, service coordinators, or RC staff with a deep understanding of the gaps in the service system and who could offer specific and actionable insights on how to enhance the service system.
- We should consider the needs of Indigenous Latin-Americans who speak languages other than Spanish, as they may face additional challenges in accessing services that should be considered in the development of the master plan.
- We should offer input and engagement opportunities scheduled for working parents to participate during then non-traditional 9-5 working hours.
- Some communities have raised questions regarding the feasibility of the master plan's implementation and its potential impact on the developmental disability community, particularly concerning individual diagnoses/needs.
- There is a need to prioritize constant communication and information on the master plan in plain language to ensure accessibility and understanding for all stakeholders.

CA Foundation for Independent Living Centers

- ILCs often engage with people pursuing DD services because they are not receiving services they need and need support advocating for themselves.
- There needs to be consistent, clear, and easy to find eligibility requirements for receiving RC services. ILCs hear about inconsistencies between RC's and even within the same RC for two different people with seemingly identical disability needs.
- The Master Plan needs to look for more avenues to get input from people with lived experience for whom traditional approaches may not be accessible such as people with communication related disabilities and technological access barriers.
- Individuals, families, and the education, medical, and social services providers need to believe in the abilities of people with disabilities and offer more messages of belief in the talents and capabilities of people with disabilities.
- ILC's described the "jail break" conversation with people served by RCs where the individual will say that they want to try to work and/or live independently but no one else in their life believes they can do it, but they want someone to try to help them.
- People are living longer and we need to provide more targeted supports to older adults with ID/DD and services to help people transition into older adulthood so they can enjoy their golden years just like everybody else.

Association of Regional Center Agencies

- RC leaders acknowledge the challenge of consistency between catchment areas. RC leaders have been working on this and appreciate the need to do more to make their efforts visible to others.
- In supporting consistency across catchments, there is a need to guard against uniformity of services when trying to achieve consistency of experience so that services are individualized as appropriate.
- Flagged the need for qualitative and quantitative data when measuring equity, specifically that spending more money on someone doesn't necessarily mean more satisfied individuals, or vice versa.
- RC's acknowledge the need to make the systems, not the families, responsible for managing the bureaucracy but are struggling with how to achieve that.
- There was a recommendation to conduct focus groups or input sessions specifically with bilingual and bicultural service coordinators to get their perspective.
- Some RCs are struggling to keep up with rapid changes, including new technologies, fast growth of their populations, and changing demographics.
- RC leaders are interested in learning from the equity strategies we develop for the Master Plan and how they could adapt them to their own community engagements.

DDS African American Focus Group

- In addressing equity and consistency, we should also ensure services are person-centered, not “cookie cutter”, and provided in a way that meets cultural needs.
- The Master Plan should consider macro-level considerations including how the system was created in the first place, what voice were involved in the creation, and impacts this has today including treating all clients, particularly black clients with respect and dignity.
- The Master Plan should be a living document grounded in transparency for the metrics used to measure success so that there is a way to shift over time as needed.
- We should offer opportunities for public input outside of regular business hours because this creates a barrier for many working people who want to attend.
- To support development of the Master Plan we should consider targeted statewide to surveys and focus groups of consumers and their parents/caregivers to measure satisfaction with the RC system.
- The Master Plan should consider developing targeted recommendations that are specifically intended to address needs of different communities like the African American, the Native American, for the Hispanic community.
- The robust and diverse stakeholder input efforts are appreciated but the Master Plan team needs to ensure that the input received is organized and made available in ways that will be useful for development of the Master Plan.

Integrated Community Collaborative

- RC's and their staff should strive to make consumers feel like they are on their side, even when they cannot provide what the consumer is asking for.
- Treating everyone with empathy, compassion, and dignity should be a core part of the culture at all RC's.
- Families don't know what is available to them so RC's should be intentional to inform them of their options and how to access them.
- The RC system as a whole should focus demonstrating transparency and earning the trust of all communities they serve.
- Families with children that may sometimes harm themselves live in fear that their children will be taken away and the RCs and other related service systems do not provide adequate support or understanding.
- Consistency is not the same as cookie cutter. RC's can provide consistency across catchment areas and still provide individualized person centered services.
- Families should have a clear and well understood options and remedies when they are made to feel intimidated or threatened when requesting services.
- Regardless of the actual policies, the experience of many families engaging with the RCs is a culture of “no”. How do we shift that to a culture of “yes”.

- Consumers who do not become eligible for RC services before the age of 18 experience significantly greater barriers to access. There should be specific and system wide strategies for supporting these individuals.

Service Access & Equity Monthly Meeting

- Early start is small but complicated part of entire system, and families sometimes don't know about the program at all or don't learn about it until it's too late to benefit.
- Workgroup members need to understand laws and funding streams in order to inform their work on the Master Plan.
- There is a need to coordinate with and learn from other Master Plan efforts, including the CA Early Childhood Master Plan and the Master Plan on Aging.
- We must recognize that no committee of any size can represent all of California's communities and we must create the vehicle to adequately represent all voices.
- The MP should be a live document that prioritizes flexibility so it can change over time with changing needs.
- The workgroups should develop their recommendations with the reality of resources and budget constraints in mind so that their recommendations will be achievable.
- The Master Plan should explore and identify successful models from other states that could be replicated or adapted in California and also look to technological solutions from private industry to take some work of families and service providers.
- There should be specific recommendations for addressing how we will serve the needs of individuals after their parents pass away so that the individual and parent can have peace of mind.
- The DD system is a three legged stool of the families and individuals, the RCs, and the CBOs, but the CBO perspective isn't always considered.

Family Resource Centers Network of California

- The MP should imagine the system with a different structure than RCs, in addition to thinking about changes to the RC system.
- Systems need to address the prejudice around disability type.
- The Master Plan must focus on people who are in the traditional system. Not everyone wants to be in the Self-Determination program
- There is variation in the services people receive and their experience with the service system. These include historic and systemic bias in the system, difficulty finding providers in more rural parts of the state and lack of seamless systems which cause delays because of multiple intake processes
- There are increased behavioral health needs. Those services are hard to access and DD services don't easily adapt to increased level of need.

- It is hard to get services during a crisis. It is not helpful to tell families to call the police when in some communities people are fearful of police interactions and their family member's safety.
- We do not provide adequate pay, benefits or training for direct care staff. The best program plans are only as good as the person implementing the plan
- We have to think about higher rates of pay and other ways to provide services in rural areas.

Summer Institute on Neuro- developmental Disabilities

- We should look at other Master Plan efforts and at what successes other states have had with reforming their DD systems for lessons that could apply here.
- After the Master Plan is finished in March, there should be a clear process for communities to stay engaged, monitor success, and keep informing whether the Master Plan is working or needs to be changed.
- Getting services from RCs requires time, resources, and privilege. Families that lack these things get fewer services when these are the families that RCs should be going the extra mile to make sure they serve.
- Many families do not feel empowered to persist or understand what they are entitled to when they are unsuccessful in getting services after their first attempt.
- Even when information is provided, if the information is not provided in plain language and in the preferred languages of the family then it is still not adequate.
- There is high turnover of front line staff providing services because the work is very challenging, emotionally intense, and poorly compensated.
- There should be specific strategies to focus on identifying and serving consumers ages 0-3 because this is often when service can have the greatest lifelong impact.
- RC's should consider additional services for families that face greater barriers to access, such as follow up communication in multiple modalities, vouchers for ride share services to address transportation issues, and flexible hours for services.
- Service coordinators sometimes feel as desperate and confused as the families because navigating all of the different systems and understanding who is responsible for what and what is allowable is very complex and challenging.

Community Engagements for Future Report Outs

- DVU Communication Access Connect Group
- Statewide Ethiopian Parents Support Group
- El Arc de California
- "Chai, Coffee, and I" with South Asian families
- Tribal Developmental Disabilities Symposium
- Convening with Rural NorCal Communities
- Focus Groups series with Service Coordinators

- Korean Families Support Group