

# Overview of Master Plan Community Engagements

Prepared for the December 11<sup>th</sup> Master Plan Stakeholder Committee Meeting

HOST	COMMUNITY	DATE
CA Association of Health Facilities Conference	Non-profit trade association representing skilled-nursing facilities and intermediate-care facilities for people with intellectual disabilities	10/02/2024
Tribal Developmental Disabilities Symposium	Tribal families in DD community and Tribal DD Service providers	10/10/2024
Valley Mountain Regional Center LVAC	Local Volunteer Advisory Committee to the Regional Center (SDP LVAC)	10/17/2024
Northern L.A. County LVAC	Local Volunteer Advisory Committee to the Regional Center (SDP LVAC)	10/17/2024
SSF Families Engagement Forum	Parents of people with DD from South San Francisco and surrounding area	10/24/2024
Sac6 Area Listening Party	Convening for just self-advocates from six counties in the Central Valley	11/01/2024
Service Coordinators Focus Group	Focus group for SEIU member service coordinators from 10 regional centers	11/01/2024
Deaf Community Engagement Meeting	Convening for Deaf and hard of hearing individuals receiving DD services	11/04/2024
Korean Community Listening Session	Forum for Korean families and individuals receiving DD services	11/07/2024
CFILC Quarterly Meeting	Update on the Master Plan to leadership of California's Independent Living Centers	11/07/2024
DD Councils of the East Bay Convening	Convening with the DD Councils of Alameda and Contra Costa Counties	11/13/2024
NBRC Board Meeting	MPDS Presentation to the Board of the North Bay Regional Center	11/18/2024

## CAHF Conference

- Even though there are perceptions that all beds are utilized, many Intermediate Care Facility (ICF) beds are empty, making the current model unsustainable.
- When infrastructure (homes or sites) is lost due to bed underutilization it can be very costly to acquire new space given the housing market.
- Client placements often go to community care homes first, and ICFs believe they are used as a last option by Regional Centers (RCs).
- Clients can face long delays for day program service authorizations, which limits client access to ICFs.
- ICFs are interested in providing end-of-life care as an option for residents.

- ICFs want to partner with Department of Developmental Services (DDS) to update their model if changes are needed, including reducing overall bed numbers.
- Competing with higher local wages makes staffing difficult for ICFs.
- ICFs request clearer communication and transparency with Regional Centers and DDS on all requirements and procedures.
- ICFs would like to find way to partners with DDS and others to ensure RCs and families better understand the wide array services and support they provide.

## Self Determination Program (SDP) LVAC – VMRC and NLARC

### VMRC

- Financial Management Services (FMS) need better quality controls and accountability.
- FMS should hire more trained staff and make timely payments to avoid losing vendors.
- Parents feel that penalties should be applied when FMS payments are late.
- Few people have joined SDP and the reasons why need to be studied, better understood, and shared transparently.
- Service Coordinators (SCs) need more training on the self-determination process.
- Flexibility is needed to allow family caregivers to provide certain medical support that they may be better suited to provide than a service provider.
- Special education programs lack sufficient support and accountability for students.
- Parts of vetoed SB1281 should be reviewed for inclusion in the master plan.
- FMS monitoring and sanctions are needed to address service quality and abuse issues, and so there are remedies for families that are impacted.

### NLARC

- Getting started in the SDP is hard, and independent facilitators (IFs) are critical, but more high-quality training is needed.
- Service Coordinators (SCs) often lack clear guidance on SDP and give conflicting information. The system struggles to attract and retain SCs.
- There is a need for SCs who specialize in SDP or dedicated SDP teams in Regional Centers (RCs) to improve continuity and reduce repeated efforts for individuals in the program.
- Simplify and add flexibility to the SDP spending plan process and involve FMS from the beginning for better alignment.
- Create a single portal accessible to all parties (service recipients, RCs, IFs, FMS, and vendors) to improve communication and transparency in the SDP.

- Recommendations for DDS and RCs to adopt a universal vendor invoicing system and client data system to streamline operations and oversight in SDP.
- DDS should collect data on SDP participation and services utilized by different cultural communities to better understand and target equity issues.
- RCs should actively promote SDP to providers unfamiliar with it to expand access.
- Consequences are needed when RCs don't follow established timelines or when FMS doesn't adhere to the spending plan to ensure accountability.

## Tribal Developmental Disabilities Symposium

- Create standards and identify funding opportunities for Tribal communities based on their history and needs. Use examples from other systems like the Indian Child Welfare Act.
- Train workers to listen, show support, and build trust with families. This would be enhanced by focusing on hiring people with lived experience.
- Share clear and open information about state plans and programs. Help local communities understand how changes will help them.
- Offer virtual services with support for technology access and training. Let Tribal groups lead some service processes.
- Enhance the workforce, especially in difficult to fill positions, by hiring peers, youth, and retirees, and give extra pay for workers traveling to remote areas.
- Help staff stay in jobs by giving them fast, high-quality training. Look for workers with values and skills that fit this work and recruit for workers on reservations.
- Maintain benefits for people with lifelong conditions. Stop rules that make them reapply for the same benefit when the qualifying condition will never change.
- Use ideas from rural programs like Migrant Education program to improve services in hard-to-reach areas.

## San Francisco Autism Society

- Regional Centers need clear rules, training, and tools to ensure fair and transparent processes for families and individuals, including those with conservatorships.
- Improve access to services for people with high support needs, like creating smaller caseloads, clear communication, and dedicated providers for complex cases.
- Expand housing options beyond traditional models with innovative solutions like ADUs or community-based "village" concepts, while planning early for long-term housing needs.
- Address gaps in support for diverse groups, such as immigrants, late-diagnosed individuals, and families managing Self-Determination Program (SDP) responsibilities.

- Create tools like online accounts, automatic receipts, and FAQ resources to simplify communication and streamline service access.
- Invest in workforce development through scholarships and training programs, prioritizing staff with lived experience and values aligned to disability support.
- Review and reform service provider systems to avoid delays, denials, or restrictive placements, and incentivize providers serving those with the most complex needs.
- Rethink models for care and coordination to better support individuals and families, including reforming incident reporting and enhancing transparency.

## Sac6 Area Listening Party

- RCs should improve communication, offer regular updates in plain language, and ensure individuals know who to contact.
- SCs need more training and autonomy to provide timely, accurate information.
- Individuals should have more control over their IPP meetings, including the ability to invite support members and run the meetings themselves. If this is already a requirement, it should be explained and enforced consistently because this is not the experience of many people.
- There should be a greater focus on independent living services, including more transportation supports, supported living for families, and options prioritizing independent living over group homes.
- Access to generic services like Medicare and IHSS should be simplified. More outreach efforts are needed to help individuals navigate service application processes and to maintain the eligibility.
- SCs should help individuals find and keep jobs by creating networks with employers, providing clear job descriptions, offering job coaching, and educating employers about disability accommodations. More agencies should assist with job searches and workplace support.
- To attract qualified workers, RCs should offer comprehensive training programs and consider life experience alongside academic credentials. Driving should not be a mandatory job requirement because this creates a barrier for qualified people with lived experience.
- Better planning is needed for transitions from school to adulthood and from adulthood to aging, ensuring individuals receive the services they need without delays and are prepared before the transition happens.
- There should be more focus on explaining things to people with developmental disabilities so they are empowered to make their own choices for themselves.
- RCs should expand options for people to make decisions about their lives, including job choices, educational opportunities, and healthcare, and ensure services like transportation and healthcare are accessible.

## Service Coordinators Focus Group

- Service Coordinators (SCs) face significant salary variations, with entry-level pay as low as \$22 in some RC with others paying twice that, despite RCs receiving uniform funding. This creates inequity and leads to high turnover.
- SCs feel their work is more administrative than service-oriented. Excessive paperwork, frequent system changes, and case management processes discourage result in more administrative and service work.
- SCs feel they play roles beyond coordination, including crisis intervention, legal advocacy, and case management.
- The existing caseload formula has not been updated since the 90s, leading to inflated caseloads and inadequate staffing. Some SCs carry 90+ cases and don't have the time to provide thorough, personalized support to families and consumers.
- One strategy to address high caseloads is more utilization and hiring for enhanced caseloads (smaller caseloads focused on individuals with low service utilization) and specialized caseloads (caseloads focused on populations with specific needs).
- High caseloads also reduce SCs' ability to provide timely, personalized support to clients, especially in complex cases like the Self-Determination Program (SDP).
- SCs require training in the CA developmental disability system, policy processes, crisis intervention, and various support services. Current training is inadequate, leading to high attrition.
- Suggestions include formal recognition programs, loan forgiveness for tenure, tuition reimbursement, dependent healthcare, flexible schedules that would also meet the needs of families, and monetary retention bonuses for long-term service.
- Remote meetings and streamlined processes, including authorizations for services and exemptions for processes, would reduce time and administrative burdens, allowing SCs to focus on clients' needs.

## Deaf Community Engagement Meeting

- Increase accessibility to resources for the Deaf/Hard of Hearing (D/HH) community in rural and underserved areas, including independent living services, transportation, and employment support, with specialized training for transportation providers on D/HH culture.
- Provide comprehensive resources and support for families of D/HH children, particularly those navigating the system for the first time or relocating, focusing on rights and processes.
- Develop a person-centered approach in the Self-Determination Program, ensuring services are tailored to individuals' needs and promoting fair wages and culturally respectful care.

- Improve transparency in service waitlists, wait times, and interpreter quality, including monitoring Certified Visual Interpreting (CVI) availability across regional centers to ensure efficient service delivery.
- Invest in Deaf-centric programs that foster cultural identity, prioritizing hiring Deaf staff and training staff to understand Deaf culture and DeafPlus needs.
- Implement competitive wages and benefits for support staff, including bilingual pay and mileage compensation, to enhance recruitment and retention, especially for rural areas.
- Provide specialized training for staff working with DeafPlus clients, ensuring they are equipped to offer culturally competent, person-centered care, including training on intersecting disabilities like autism and DeafBlind services.
- Expand employment support and internships tailored for D/HH individuals, with ongoing support from job coaches or case managers to help with long-term employment and professional development.

## Korean Community Listening Session

- Consumers report inconsistent service delivery. RCs need to ensure accountability, maintain consistent eligibility criteria, and streamline approval processes, especially for assistive technology (AT) and physical therapy (PT).
- Service Coordinators need ongoing training, particularly in available services, cultural competency (especially with Korean-speaking families), and effective communication to improve service quality and reduce language barriers.
- The approval timelines for RC services are often excessively long, creating unnecessary delays; improving billing systems and introducing electronic processing could help expedite services and reduce financial hardship.
- Language and cultural barriers, particularly within Korean communities, need to be addressed through better language support, culturally relevant training for staff, and the hiring of more Korean-speaking staff.
- Financial Management Services (FMS) require better staff training to ensure clarity, efficiency, and improve processing times to reduce delays and errors.
- Increased collaboration between departments and a third-party system for complaints and audits would help address service gaps, ensure transparency, and improve accountability.
- Family involvement in the process should be supported by providing clearer, timely, and culturally appropriate documentation, including translations of IEP/IPP documents.
- RCs should hire additional staff to reduce the caseload burden on SCs, improving service delivery and communication. Additionally, extending services before expiration and improving the spending plan process will help prevent service gaps.

## CFILC Quarterly Meeting

- Provide culturally accessible training for parents on fostering independent living skills and future planning to help their child become independent.
- Encourage regional centers to start transition planning earlier (from high school) and ensure that they focus on the individual's vision for their future.
- Expand the range of vendors at regional centers to offer more internship and workforce opportunities. Improve support for individuals facing additional challenges (e.g., foster care, juvenile detention, homelessness).
- Ensure that annual reports to consumers are clear and accessible. Hold regional centers accountable for consistent service delivery and ensure individuals receive all services included in their paid packages.
- Facilitate "warm handoffs" from regional centers to other organizations like independent living centers, and ensure service coordinators are better trained on external community resources.

## DD Councils of the East Bay Convening

- Establish clear processes for accountability, including a complaint resolution process and oversight mechanisms for Regional Centers (RCs) and the Department of Developmental Services (DDS).
- Implement Results-Based Accountability (RBA) in the Master Plan with measurable goals, defined timelines, and regular progress reports.
- Create a structured process to operationalize goals and develop a dashboard to track success and progress across regional centers.
- Form an advisory committee for each regional center to foster collaboration across the state's regions and encourage regular meetings to improve service consistency.
- Develop a multi-lingual portal for easy access to information, incorporating AI to guide families through services and applications.
- Ensure services are consistent and portable across regions to avoid gaps when clients transition between regional centers or age out of services.
- Advocate for the inclusion of Medi-Cal, IHSS, and school representatives in workgroups to integrate services and facilitate secure information sharing between systems.
- Involve families in the application and intake process by offering feedback opportunities (e.g., surveys, customer service questionnaires).
- Reevaluate barriers that delay service delivery and address challenges within the Social Security system, including overpayment issues and follow-up needs.
- Encourage RCs to develop stronger community collaborations, focusing on supportive roles beyond just funding services for families, clients, and providers.



- Provide families with easy-to-understand application processes, on-site or virtual assistance, and resources such as manuals detailing transition services.
- Conduct periodic reviews and solicit stakeholder feedback to refine services and processes.

## NBRC Board Meeting

- Individuals with developmental disabilities (DD) are at a higher risk of sexual abuse or harm, necessitating stronger accountability measures for RCs and DDS when abuse or neglect occurs. More leverage is needed to address bad actors.
  - There is a need for services to train individuals with DD on healthy relationships, self-advocacy, and safe dating practices.
  - The medical model of disability, which emphasizes compliance without input from individuals with DD, is a significant problem. A bill of rights created by people with DD is necessary to address this issue.
  - Individuals with DD often don't learn about available resources until issues are already serious. A comprehensive list of resources should be made available to help prevent this.
  - Mental health services for people with DD need to be improved and better coordinated with the broader DD system.
  - Providers should be required to ask if an individual wants an advocate present for appointments or services, similar to how they ask about translation needs.
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## Community Engagements for Future Report Outs

- South San Francisco Family Engagement Forum
- Level Up! African American / Black Families Group
- Family Soup: Northern CA Communities Listening Session
- Congreso Familiar
- El Arc Input Session Updates
- ARCA Partners in Policy Making
- UC Irvine Center for Autism