

Overview of Master Plan Community Engagements

Prepared for the January 8th Master Plan Stakeholder Committee Meeting

HOST	COMMUNITY	DATE
South San Francisco Family Engagement Forum	Group of families of individuals served by the system that meet monthly to discuss issues and share experiences.	9/10/24
Level Up! African American / Black Families Support Group	African American/ Black Families Support Group's mission is to provide and ensure that people with developmental disabilities and their families have equitable access to information, resources, services, and advocacy skills that facilitate empowerment.	11/21/24
Congreso Familiar	Congreso Familiar is a collaboration of parents, professionals, and community agencies. The goal is for families to gain new skills and knowledge so that they can better respond to the needs of their family member with disabilities.	12/2/24
ARCA Partners in Policymaking	Partners is a leadership training program for adults with developmental disabilities and parents of children with developmental disabilities to teach best practices and the competencies needed to influence public policy.	12/5/24
UC Irvine Center for Autism	UC Irvine Center for Autism hosts regular forums to discuss issues and share experiences. This forum was focused on the Latino community.	12/13/24

South San Francisco Family Engagement Forum

- Streamline service access: Make the process for applying for services easier by reducing duplicate processes, paperwork and using simpler language. Ensure services are accessible, especially for those with complex medical needs.
- Improve pay and staffing for providers: Increase compensation for providers to prevent staff shortages and burnout caused by workforce shortage. Address the imbalance between pay rates in the DD system and other industries to attract and retain qualified professionals.
- Address inequities in the Self Determination Program (SDP). SDP should be made more accessible to all, not just those with the resources to navigate it. Alternatives to

SDP must be available for those who cannot or do not want to participate in the program so it does not further inequities.

- Increase support and awareness for career development in DD services: Encourage careers in developmental disabilities services through state and local partnerships, offering incentives like increased benefits or student debt forgiveness.
- Better communication and support for deaf individuals: Ensure better accessibility and support for Deaf individuals within the DD system, addressing issues of isolation and communication barriers.
- Increase transparency in funding and resource allocation: Clarify how funds from state-run facilities have been reinvested and ensure there is an accounting of this spending that can be accessed by the public.

Level Up! African American / Black Families Support Group

- Communication and transparency issues: Families often don't get clear answers from Regional Centers. Services are sometimes denied without explanation. Service coordinators are not always aware of available services.
- Navigating services and insurance: Families are confused about when to use the Self-Determination Program (SDP) and when to use insurance. They want the option to start with SDP and switch to insurance later because insurance coverage does not always become available when it is needed.
- Timeliness and proactivity: There are delays in getting services. IPPs can take several months to complete. Families have trouble reaching RC staff and getting timely responses. Information about services is not provided on time. Families need more proactive help, especially after leaving K-12.
- Support for families and service coordination: Parents often rely on other parents for help navigating the system. Service coordinators are often too busy to give enough support. Families need more connections, especially when they are new to the system.
- Systemic gaps and resource needs: Housing, dental care, and behavioral health services are major problems. More services are needed for people with developmental disabilities and people need more transportation options to access services that are not close to where they live. Respite services should be more flexible, especially for families with other health needs.

Congreso Familiar

- Service accessibility and transparency: Ensure services are tailored to individual needs. Make services realistically accessible and transparent. Provide clear documentation and communication about available services and processes for appeal or correction

- Empowerment and support for families: Provide families with clear, accessible information. Offer orientation at diagnosis. Provide independent advocacy, especially for those from diverse backgrounds or with limited English proficiency.
- Inclusion and integration: Promote inclusion of people with DD in educational settings and the broader community. Offer job opportunities beyond the service sector. Create integrated recreational spaces like outdoor parks for families.
- Accountability and oversight: Enhance oversight of Regional Centers through independent entities. Regional Center boards should be elected through a more independent process to ensure community representation. Implement clear processes for handling complaints. Ensure corrective actions are taken when services are improperly denied or not provided.
- Employment and education support: Provide comprehensive support for employment training and internships. Support school-age advocacy. Ensure people with DD are better prepared for employment and school integration.

ARCA Partners in Policymaking

- Improve SC training and accountability: Train service coordinators in clear communication and cultural competence. Limit caseloads to ensure quality support. Recruit SCs from the communities they serve. Improve pay and career growth to reduce turnover.
- Expand access and close service gaps: Increase satellite offices and telehealth options to support rural areas and address “service deserts”. Address digital accessibility barriers like internet access and technology literacy. Fund more client rights advocates to support underserved communities.
- Simplify RC navigation: Create tools like checklists and guides to outline RC services and processes. Use a universal application to reduce confusion and paperwork. Ensure families have clear and consistent information about services.
- Enhance peer support and programs: Expand social recreation, independent living, and career preparation programs. Train peer navigators and facilitators to guide families through RC systems. Develop tailored programs for marginalized communities including for those that don’t speak English.
- Empower families and individuals: Provide training on self-advocacy and online system navigation. Support individuals and families in taking active roles in service planning. Help foster independence by allowing individuals to learn through experience.

UC Irvine Center for Autism Latino Forum

- Regain trust and improve communication: Parents need clear information about available services and processes. Many parents feel left in the dark by service coordinators and have to repeatedly ask for services.
 - Address staffing and leadership issues: There are long-term staff and leadership that are not effectively performing across the system but especially in regional centers. There should be term limits for leadership at the RCs.
 - Simplify processes and increase accessibility: Services should be more accessible with less paperwork and clearer timelines. The process for receiving services should be less complicated, less burdensome for families and more transparent.
 - Improve cultural competency and support: There is a lack of cultural and linguistic competency in services, especially for Latino communities. More support groups and advocates are needed for diverse families
 - Ensure accountability and remedies: Families should receive retroactive compensation for services that were wrongly denied or delayed. There should be a third party to advocate for families and clarify their rights, including immigration status.
 - Data analysis: Data should be collected on how many people with DD are homeless, institutionalized, and incarcerated because it is probably a bigger problem than people realize.
 - Expand services for high-functioning individuals: Families need access to appropriate services for individuals deemed "high functioning," rather than being told no services are available.
 - Promote collaboration between systems: Public joint meetings between regional centers and county behavioral health systems should be held to improve coordination and address community needs.
-

Community Engagements for Future Report Outs

- Self-Advocate Listening Parties
- Interagency Coordinating Council on Early Intervention
- The Natalie Project