

Public Comment Analysis: 2022-26 State Plan

Introduction:

California's State Council on Developmental Disabilities submitted its proposed 2022-26 5-year State Plan for (an online, 45-day) public comment (period) on September 25th, 2020 and closed the opportunity on November 9th, 2020. Individuals who took the survey were asked (in separate questions) to respond to each of SCDD's three (3) State Plan goals, which included eight (8) objectives (in total).

Over the course of its public comment period, the Council received responses from 46 individuals (e.g. self-advocates, family advocates, and others [which also included professionals in the field of intellectual/developmental disabilities]). Of the 46 surveys which were begun by respondents, fifteen (15) were left completely blank, with no comments included (an additional survey was simply a [Go Fund Me] request for money). Of the thirty (30) surveys in which comments were provided, respondents' statements fell into three (3) broad categories, including comments that were: 1) positive or approving; 2) observations, questions or suggestions; and/or, 3) criticism or critical questions/requests. Some responses contained a combination of approval and criticism or suggestions and were split, for the purpose of Council analysis and response.

Goal 1 (including 2 objectives):

The Council will empower people with intellectual/developmental disabilities to become strong self-advocates, peer trainers and community leaders.

Of the seventeen (17) public comments made about Goal 1 (Self-Advocacy/Advocacy) of the Council's proposed State Plan for 2022-26, two (2) were critical, eighteen (18) included suggestions and/or observations, and six (6) comments were positive/approving. There were seventeen (17) blank survey responses.

Absolutely amazing thank you god bless you all who decided to help and take burden off of our shoulder the parents of developmental disables, we need housing

Goal 1 is fantastic. Having opportunities for leadership and to showcase strengths. Having opportunities to advocate and seek opportunities for improvement in leadership is absolutely the right way to go. This allows self advocates the chance to grow and shine in a positive light.

I think this goal can happen

This is fine.

Yes, I agree to this objective.

We support this goal and these objectives, and want to add some detail...

Survey Responses (Goal 1):

Of the eighteen (18) survey responses to Goal 1 that were observations/questions/suggestions, there were several types of interest expressed:

- A.** 1 response identified a global (social contact/needs) issue, which was reflective of the respondent's own child's needs; 1 response reiterated the need for self-advocacy
- B.** 1 response requested that the Council reach out to rural counties
- C.** 2 responses provided an inquiry about public access to online Council training and training (specific to the use of online resources/training), in addition to a question about financial support for internet service and effective access to assistive technology
- D.** 2 responses requested that the Council pay self-advocates for their efforts as trainers
- E.** 3 responses were requests that the Council identify skills/needs, supports/services and trainings important to self-advocates (and underserved populations)
- F.** 4 responses provided suggestions about (potential) collaborative partners in the Council's work (some in the provision of specific therapeutic models)

- 1.** One of the strong needs for learning disabled people is social contact. At age 54 my LD son is isolated socially and is advised by his regional center to join a social group whose members are in the teens or 20's, which he does not want to join due to age difference. He is high on the autism spectrum. Please consider needs of such disabled people."
- 2.** The resources in rural counties are limited in many ways. I hope you reach out to counties such as Siskiyou, Trinity, etc. in ways that are accessible.
- 3.** Is a "peer trainer" a paid or volunteer position? If we want people with intellectual/developmental disabilities to be gainfully employed, the positions recommended by SCDD should be a paid position.
- 4.** Ensuring that peer trainers are paid opportunities, and incorporating capacity building for organizations to hire peer trainers and/ or advocates with disabilities would be a good addition to this objective.
- 5.** It is essential that we identify the supports & services and issues that impact the self-advocates. We need to know exactly what is problematic for self-advocates and what these are in specific detail so that we can present solutions in an acceptable manner that will do good rather than worsen their problems.
- 6.** I think it is essential that the Council identify the specific tangible skills and services and issues that are important to self-advocates so that the public can assist in whatever way possible and available and then device innovative ways to fulfill

whatever is lacking. From these issues will emerge the intangible needs that are masked by the many tangible but unfulfilled needs of the persons with disabilities.

- 7.** Working in collaboration with the Social Security Administration will be key in helping people with intellectual/developmental disabilities to learn to navigate this complex system, even with a designated payee, in order to effectively self advocate.
- 8.** Whether this is through People First or not, the SCDD needs to empower people with developmental disabilities to make decisions, hollow through on those decisions, and to be responsible and accountable for those decisions.
- 9.** You also need to help our clients learn how to manage their lives such that the successful ones can mentor others. We are having issues right now with our Boards in that our client Board members are struggling to stay on the Board and manage their own lives. We need to support them and help them learn to help others
- 10.** *We support this goal and these objectives, and want to add some detail to consider within this goal. We want to emphasize how use of the DIR/Floortime Model (and other DRBIs - Developmental Relationship Based Interventions) supports self advocacy by helping people with developmental challenges to assert themselves vs more common behavioral approaches that aim to have the person meet goals decided for them without taking their perspectives into account. California has a wealth of providers trained and skilled in this proven method throughout the state. Several of us would be willing to provide more information or training to whomever about the use of this wholistic and person-centered approach. Some additional information can be found at www.dirfloortimecoalition.com, for example. Under this Goal, perhaps most related to Objective 1 and "identifying... supports and services they need..."*
- 11.** To reach Goal 1 of Self-Advocacy, State Council could locate and support vendorization of providers who utilize intervention approaches such as DIR/Floortime which are focused on developing the individual's own interests, initiative, purposefulness, intentionality, generation of ideas, social problem-solving versus vendors and providers who utilize intervention approaches which emphasize behavioral compliance.
- 12.** Since technology is such a big deal due to COVID, networking can occur via online. Will training be provided on the use of different online platforms? Will people with disabilities be afforded internet so they can have access to online outreach events?
- 13.** This goal clearly articulates SCDD's goal to empower people with intellectual/developmental disabilities to become strong self-advocates, peer trainers and community leaders. ARCA shares this goal and recognize that in order to achieve this, people with IDD must have access to necessary accommodations and supports needed to participate in the proposed trainings. These accommodations and supports must also include the availability of technology supports.

- 14.** For objective 1, I think that the opportunity to develop and/or establish programs and/or resources that are needed is critical for self-advocacy. Instead of being limited to programs developed by those without lived experience, I think the opportunity for true self-advocacy and empowerment should allow for and enable individuals to develop programs that leverage lived experience to develop innovative, thoughtful, and solution-oriented programs to increase educational and employment opportunities. As such, objective 2 should include resources for: small business development, entrepreneurship, social impact program development, as well as a professional mentoring program. Advocacy and community leadership take many forms, and this should be forward-thinking in its approach. The days of advocates asking for things are outdated and behind us. Empowering advocates and community leaders to develop solutions is innovative, efficient, and the way of the future. Give us the opportunity to make a change; we already have a voice.
- 15.** Please consider addressing internalized stigma as a topic in one of your groups. It's hard to advocate for yourself if you don't feel good about yourself.
- 16.** What is the timeline to meet this goal?
- 17.** I would like to say one, that yes I believe we need very strong advocates and leaders. We really need to make sure that the next generation of advocates and self-advocates really understand about the advocacy movement and what the generation of people with disabilities had to fight for to get our rights. It's not enough just to say that you are an advocate, you really have to know what advocacy means and what it stands for. I want to see the next group of disabled people really fight for what is needed and for what they believe in.
- 18.** need to make sure that trainings are on subjects found in the surveys. Have to address needs of many ethnicities

Of the two (2) critical responses received about Goal 1, the first asserted that it was not written in plain language and the second remarked that the Deaf community was not specifically included.

- 1.** I can definitely tell that this one isn't written in plain language.
- 2.** How does this goal relate to the Deaf community? The word "deaf" does not appear in the State Plan.

Analysis/Response (Goal 1): Observations/Questions/Suggestions and Critical Feedback

The Council has designated Goal 1 as its Self-Advocacy goal, an area that is required by the Federal DD Act and highly valued by the Council in informing and empowering self-advocates, their families and others.

Of the eighteen (18) survey responses to Goal 1 which were observations/suggestions, there were only two (2) that (both) raised an issue not already addressed by SCDD – that of paying self-advocates for work in collaboratively providing training/presentations alongside Council staff. While not an issue that can practically be addressed in the proposed 5-year State Plan itself, it is an issue that can be raised internally within the Council and its administration as a budget/policy/practice consideration.

The issue raised about age-appropriate social activities is certainly of concern to family and self-advocates throughout the state, although it is also an issue typically addressed through the Council's annual workplan. For example, the Council recently implemented a 'Monthly Chat' with self-advocates throughout the state, moderated by its Self-Advocacy Coordinator. Managers in offices throughout the state monitor the unique needs of their own regions in developing and/or supporting activities in direct and systemic response to those needs. Headquarter staff monitors emerging issues to direct attention and/or resources to such needs as they arise at the state level, as well, including relevant activities into the yearly work plan, as necessary.

Two (2) responses related to the availability and accessibility of assistive technology and online Council training, training which has already been planned as an activity in the 2021 annual work plan, under the current 5-year State Plan. The Council has set aside funding to develop an Online Training Resource Center (as part of Goal 3) that will be designed to facilitate online (readily accessible upon request) and virtual (scheduled) trainings, both through internet access. This platform proposal will expand easily accessible training opportunities throughout the state, while allowing the Council to redirect staff resources to engage more heavily in special/regional projects and broader systems change efforts. Although this planned training portal will be funded through the Council, SCDD is neither a direct funding source nor service provider. While the California State Departments of Rehabilitation, Developmental Services (through regional centers), etc. may directly provide constituents funding for/access to internet and/or other assistive technology services (through state/federal funding), it is not permissible for SCDD to do so. This may, however, become a public funding/policy area for the Council to address in the future.

Most of the suggestions/questions/observations that were provided about Goal 1 involved collaborative work or partnerships with local, state and/or federal agencies. As part of its overall State Plan submission, the Council provides a list of partners with which it intends to collaborate through the five (5) years of the plan. Because the Council is not a direct service provider, it relies heavily on thousands of community-based, regional, state and federal

collaborative partners to provide the actual supports and services that are so important to people with disabilities (lists of these collaborative agency partners are available through the Council). SCDD then provides planning, oversight, grant opportunities, issue analysis and reports to help guide development and delivery of and assess those supports and services. One respondent asked about the timeline for completion of this goal; all 3 goals and their objectives are part of a 5-year State Plan cycle. Work plans will be developed each year, with more targeted timelines and projected numbers, but the overall State Plan will be completed over a 5-year period.

One comment raised the need for the funded development of small business, entrepreneurship, and social impact programs, in order to build self-advocacy, empowerment and experience in self-advocates. The Council currently solicits proposals and provides grant funding for innovative programs (both at the state and regional levels) that are designed to serve as pilots or proven models for future work. While the Council does not have the authorization or funding to provide for program continuity, it does rely on community-based agencies to identify continuation funding and build ways to implement long-term supports and services, based on promising practices and program innovations. In support of that model, the Council also reports (at both the state and federal levels) on successful programs and promising/best practices, at the conclusion of each of its grant program cycles.

Finally, two respondents raised issues regarding self-advocates themselves: 1) identifying personal lack of self-esteem as a potential barrier to fully achieving self-advocacy, and 2) the need for self-advocates to drive their own advocacy efforts, rather than expecting the Council (and other agencies) to speak for them. The Council is firmly committed to empowering self-advocates through Goal 1 – both by supporting self-advocacy groups and through training self-advocates to (themselves) begin providing peer-based training about governance, self-determination, person-centered planning, etc. Additionally, the Council’s newly implemented Monthly Chats (with self-advocates throughout the state) are designed to draw out and improve the self-esteem and capacity of self-advocates throughout California.

Regarding the critical responses received about Goal 1, the Council works to address both state and federal requirements in providing resource materials and other information in plain language (SCDD provided a plain language version of the proposed State Plan for public review). Many terms used in the Council’s proposed State Plan are disability-specific and not found in daily language used by most people. These terms and words are also difficult to translate into threshold languages, because they are ‘conceptual’ or complicated ideas that are not often (if ever) used in many languages and cultures. The Council has developed a lexicon of these terms with plain language definitions (in English). These definitions are too long to include in most state and federal reports but are available through the Council. SCDD’s plain language definitions are also available (at no cost) to companies and individuals providing translations.

A final note of criticism, in response to Goal 1 (as well as Goals 2 and 3), stated that there was no (specific) mention made about the Deaf community, which is accurate. While there are people with intellectual/developmental disabilities who also have sensory impairments (e.g. vision, hearing, etc.), SCDD does not restrict itself to identify or work with specifically named populations of people with disabilities (e.g. the Deaf/Hard-of-Hearing population, etc.), outside of those individuals with intellectual and/or developmental disabilities.

Of the 306,179 people served by DDS (DDS, 2020, pg. 2, *Consumer Characteristics at the end of September 2020 - Statewide*), 48,945 people have a vision or hearing impairment – or both hearing and vision impairments. In fact, the Council’s practice is to serve people with intellectual/developmental disabilities and/or cross-disabilities, as issues that affect people with one type of disability typically affect the civil, service and/or support/access rights of people with other disabilities, as well. Activities designed to address disability-specific access issues are part of the Council’s annual work plan; how those activities are provided/implemented at the regional level is part of each *region’s* annual strategic work plan.

Staff Recommendation (Goal 1)

The responses (for Goal 1) submitted during the public comment period addressed questions or concerns that: 1) are already part of the proposed 2022-26 State Plan, or 2) may be integrated into annual work plans throughout the course of the 5-year State Plan period.

At this time, staff is making no recommendations for changes in Goal 1 of the proposed 2022-26 State Plan (as written).

Goal 2 (including 3 objectives):

The Council will lead in partnership with family/self-advocates and others to protect and enhance civil rights and improve community-based systems to be more fully inclusive and supportive of people with intellectual/developmental disabilities and their families.

Of the 29 public comments received about Goal 2 (Systems Change/Advocacy) of the Council's proposed State Plan for 2022-26, five (5) were critical, seventeen (17) included a combination of positive comments, suggestions and/or observations, and six (6) comments were positive/approving. Another 23 survey responses were left blank (with one additional response that was part of a request for money).

Great idea

I LOVE this goal!!!

It's a wonderful idea to help parents and family of intellectual/developmental to get involved and increase their ability to advocate for their loved one.

The goals sound promising....

We support this goal and these objectives...

Yes, agree to this objectives. We have to continue to keep the civil rights from infants to seniors people with disabilities.

Survey Responses (Goal 2):

Of the seventeen (17) survey responses to Goal 2 that were observations/suggestions, several areas of interest/comments surfaced:

- A.** Two comments raised concerns regarding the capacity of both peer trainers and activity participants
- B.** One comment raised a need for reimbursement of legal fees (for parents/clients) in cases involving regional centers
- C.** Five (5) responses requested the Council's attention in one (1) of four (4) specific areas:
 - 1)** Employment
 - 2)** Housing
 - 3)** Law enforcement training
 - 4)** Access to/service disparities regarding regional center services (specifically for underserved populations)

- D.** One individual requested that the term 'advocates' be expanded to include community advocates, in addition to family and self-advocates
- E.** One comment expressed hope that the UCEDDs would consider the needs of all persons with intellectual/developmental disabilities, extending beyond just those of children, aged 0-12
- F.** One comment drew attention to potentially beneficial programs/collaborative partners; two comments requested program expansions, including an amendment to the Lanterman Act
- G.** Final comments questioned the metrics that will be used to determine the qualitative progress or success (outcome[s]) of this goal and the timeline for the goal's completion

- 1.** Objective 1- please focus specifically on service codes to support employment. TDS is the only service code that currently funds at a sustainable rate for 1 to 1, flexible support, and the hours allowable are usually very low. When people are served under variable ratio service codes the WILL NOT achieve goals of real, competitive, gainful employment. Supported Employment service codes, at least with ACRC, do not fund job development- just job coaching once a job is found. This is a huge problem and results in countless people being denied employment services.
- 2.** Families need to be educated on the importance of working, including how working can and may impact benefits. Many families are fearful of benefits being cut; therefore encourage their family members with a disability not to work. Employers have also been fearful of hiring people with disabilities due to fear of liability and lawsuits for discrimination if they let go of the individual with a disability. Education to the community and employers is also important.
- 3.** Housing is much important.
- 4.** Employment is critical to our clients to achieve their full potential. We would like to see MORE active promotion of job opportunities and trainings that prepare our clients for the workforce, MORE liasons with industry to help them be more inclusive of our clients in their workforce, and help industry develop more internships and training opportunities for our clients. We want to see a BIG uptick in our clients achieving gainful employment.
- 5.** This should include teaching the police how to appropriately interact with people with disabilities.
- 6.** The State Council could better reach Goal 2 to protect civil rights of people with intellectual/developmental disabilities who are underserved by the Regional Centers by adding an objective. An additional objective needs to be added to reduce disparities between Regional Centers and between client populations at Regional

Centers. Many families of young children believe there are no services available after age 3. Many families of certain Regional Centers never hear that there could be home-based developmental services provided for their children or adolescents. Certain neighborhoods and certain families in the know (highly educated families) learn independently from other families that they are able to request Regional Center funding for urgently needed social-emotional 1:1 in-home developmental intervention (DIR/Floortime) and adaptive skills training for their school-age children and older children. Families in immigrant or urban communities are typically not informed and never know they can request support. Certain Regional Centers do not vendor these services. Vendorization in a home Regional Center should be automatically recognized in other Regional Centers to reduce these vast disparities in service to individuals from lower income communities.

- 7.** Goal 2 should be expand "family / self-advocate" to include community advocates, such as those on the RAC committees.
- 8.** It is important that the medical an psychological and intellectual makeup of the self-advocates are known to the trainers or facilitators and how they reflect the population they represent. This would be difficult because not one individual is totally alike to another just because of a common diagnosis. Each individual has his own set of talents, abilities as well as disabilities and we have to work with all these in training each self-advocate, who might be there for his own reasons and not necessarily reflective of the community or the sample of the population of persons with disabilities. Most of the neophyte self-advocates would be bringing his own agenda as he is not yet exposed to the general population of the disability community. He primarily knows what he needs or what his family needs or those who he has come in contact with. But I think this will change over time and interaction with others.
- 9.** It is also a consideration that the medical, including the psychological and intellectual, makeup of individuals with disabilities are given primary attention because we have to tailor the generic service system to the basic and intermediate needs of these individuals according to their bodily physiological emotional and intellectual interactions in reacting to various stimuli which can be varied and intertwined unless specifically modulated and temporally provided. I fear that for some it can be overwhelming and dangerous at least medically or emotionally. On the other hand, given that each person is unique and possesses a unique set of abilities and disabilities, if we learn how to handle possible setbacks, our self-advocates with adequate supports can provide the world in general with perspectives unique and exciting as these are born out of experiences unique to the disability world.
- 10.** A fee provision should be added, such as the provision in IDEA. If a family member/consumer/caretaker needs to obtain a lawyer to receive needed services from regional center, then regional center is responsible for paying for the attorney's

fees if the claims are valid; See: <https://sites.ed.gov/idea/regs/b/e/300.517>. This will facilitate more transparency, better quality services and better outcomes for consumers.

- 11.** The goals sound promising. Hopefully the university centers will not limit their expertise to the 0 - 12 yrs. of age groups, but expand to include all age groups.
- 12.** ...we want to emphasize how use of the DIR/Floortime Model (and other DRBIs - Developmental Relationship Based Interventions) supports self advocacy by helping people with developmental challenges to assert themselves vs more common behavioral approaches that aim to have the person meet goals decided for them without taking their perspectives into account. California has a wealth of providers trained and skilled in this proven method throughout the state. Several of us would be willing to provide more information or training to whomever about the use of this wholistic and person-centered approach. Some additional information can be found at www.dirfloortimecoalition.com, for example. More knowledge/awareness and/or use of this approach more widely might help improve outcomes related to these objectives.
- 13.** ARCA appreciates that this goal focuses on protecting and enhancing civil rights and improving community-based systems to be more fully inclusive and supportive of people with intellectual/developmental disabilities and their families. In fact, this goal specifically aligns with ARCA's strategic goal related to inclusive communities. With respect to the Council's plan to develop, improve and/or change practices, policies, and regulations and/or laws in the systems of regional centers, community-based services, and governmental entities, ARCA agrees these strategies are important to promoting full inclusion and protecting the civil rights of individuals with intellectual/developmental disabilities, but believes it is not the number of changes made but their impact that is most meaningful. It is important to note that making changes to practices, policies, and regulations in and of itself does not necessarily provide a good measure of progress in these areas. ARCA recommends using a different measure for progress based on outcomes for persons with developmental disabilities.
- 14.** Hello - I am a parent of a RCOC client who is participating in the Self-Determination program. It has been AWESOME and given us flexibility, especially in light of COVID concerns, to structure the services my son needs. We will likely spend less than the original budget because we are using individual providers instead of agencies for many of his services. I highly recommend expanding this program. I also suggest that the state increase the amount of money families can contribute to a CalABLE account. It is very expensive to support a person with a disability.
- 15.** The Lanterman's Act MUST BE AMENDED to include that the Regional Centers will pick up the cost of attorney and advocates that a family requires in order to take on the RCs. Local RCs should be required to supply a list of advocates and attorneys in

the area that have experience in legal action against the RCs. The RCs know who does this work -- we the consumers do not.

16. What is the timeline to meet this goal?

17. How are you going to count these? I dont see any charts or graphs about yu programs or services.

Of the five (5) critical responses received about Goal 1, the first remarked that the Deaf community was not specifically included and the second requested a specific housing objective. Two (2) remarks involved the measurability of the goal and objectives and the identification of only four (4) federal partners (Objective 2.3). The final response expressed the need to have self-advocates share their collective experience/voices in creating systems change.

- 1.** Housing seems to be an important goal for all right now. It should have its own objective, as if housing needs are not meet, no other objectives matter.
- 2.** How does this goal relate to the Deaf community? The word "deaf" does not appear in the State Plan.
- 3.** Objective 2 is lacking clear verbiage on how we are empowering and how services will be increased.
- 4.** The goal and objectives read like a bad IEP where you don't have baseline data so you can't understand or identify measurable progress on this goal. For Objective 1, what practices, policies and regulations are being targeted and why? For Objective 2, which regional and state-wide projects are being targeted and why? For Objective 3, why these four partners?
- 5.** This doesn't mention the inclusion of self-advocates having a voice or opportunity to participate in any of the activities listed above. If Goal 1 is about self-advocacy, then shouldn't Goal 2 build on that by including self-advocates in the work being done to ensure that their lived experiences are used to inform decision making?

Analysis/Response (Goal 2): Observations/Questions/Suggestions and Critical Feedback

Goal 2 is the Council's designated public policy/advocacy goal. The Council and its Headquarter and regional personnel will engage in systems change efforts and advocacy through this goal, its three (3) objectives, and annual work plan(s)/associated activities.

Of the seventeen (17) survey responses to Goal 2 which were observations/suggestions, there were only two (2) issues raised that have not been addressed by SCDD – specifically that of: 1) determining/responding to variations in peer trainer/trainee capacity, and 2) a request for the reimbursement of legal fees incurred as a result of individual/family disputes/legal proceedings against regional centers.

In regard to training/information, technical assistance and resources provided to family and self-advocates, the Council typically provides its training and materials in plain language for the purpose of accessibility. When requested, translations are provided for training, with materials provided in the language of preference. The Council is always in the process of reviewing and translating training, resources and handouts. SCDD's staff also uses a language line for phone calls and requests for technical assistance from those who don't speak English. Because every individual (regardless of ability/disability) has unique abilities, preferences and needs, SCDD does not judge or limit the capacity of anyone – including self-advocates - to attend and/or to provide peer training. Council staff will, however, provide assistance, training and materials and often (though not always) partners with family and/or self-advocates in training or presentation opportunities.

The request about reimbursement for legal fees (associated with regional center disputes) may be addressed as a policy-related issue through the Council's annual work plan, based on recommendations by either or both the Council's State Plan (SPC) or Legislative and Public Policy (LPPC) Committee(s).

Two (2) responses drew attention to the Council's partnerships with its state, federal and community-based partnerships, something that is critical to SCDD's success throughout the state. And, while the Council does not endorse specific therapeutic strategies, it does provide grant opportunities to agencies and individuals in its yearly request for proposals and assignment of grants to develop and demonstrate innovative ways of serving people with intellectual, developmental and/or cross-disabilities in California. While the Council partners with hundreds of agencies/individuals, it does not direct its collaborative partners in the populations they serve or their work *outside* of partnership efforts with SCDD.

One survey response asked that the Council expand its roster of advocates (as described in its objectives) to include 'community advocates,' especially in light of those people serving on SCDD's Regional Advisory Committees (RAC). In fact, the Council relies and calls on the many advocates providing supports and services to people with intellectual/developmental disabilities throughout the state - those serving in paid and/or volunteer professional and community-based positions. Because of the complexity of the system of services and supports and diverse communities, the Council acknowledges and celebrates all of its community partners with the term 'others.'

Six (6) observations/suggestions requested that the Council address needs in specific, identified areas (e.g. employment, etc.), all of which are included within the objective language and will be further described in annual work plans for each of the five (5) years of the proposed 2022-26 State Plan. One respondent asked about the time period assigned to each goal. As discussed in the Goal 1 analysis, the State Plan period is 5 years, although annual work plans will be submitted (and reported on) for more specific activities.

Two (2) responses included, in order, a request to: 1) expand the Self-Determination Program (SDP); 2) increase the amount of money that can be contributed to CalABLE accounts; and, 3) amend the Lanterman Developmental Disabilities Services Act to require

regional centers (RC) to pick up the cost of attorneys and provide lists of available advocates/attorneys, in cases of legal disputes between the RC and its clients and/or families. While these are all recommendations about policy-related work that may be included in the Council's annual work plans, they are too specific to include at the goal or objective levels.

Of the four (4) critical comments submitted during the Public Comment period about Goal 2 of SCDD's proposed State Plan, the first was a strong request for a housing objective. As mentioned previously, housing is one of the areas specifically identified as a priority within Goal 2 and will be addressed more specifically within each annual work plan. The second criticism – like that addressed in Goal 1 – was that the deaf community was not specifically mentioned. Please see the analysis included with Goal 1 for a discussion of this issue.

The final critical response identified concerns with the measurability of the goal and its objectives, as well as the identified collaborative agency partnerships. The State Plan is submitted in 'layers' of goals, objectives, and yearly work plans (with very specific, achievable activities). Federal guidance has been that goals should be "broadly specific" in identifying areas of desired change, while objectives are designed to be more measurable, in targeting more specific changes and the number of people to be reached. Baseline statewide data is provided in the Comprehensive Review and Analysis (CRA), which is part of the larger 5-year State Plan submission, due in August of 2021.

Specific activities (and the Council's projected numbers of activities, people reached, policy/practice changes, etc.) are part of SCDD's annual work plan, which is revised and submitted to the federal government with the Council's Program Performance Report (PPR) at the end of each calendar year. It is in those annual work plans that projects are identified (either as in-house Council efforts or grant-funded projects). The Council's LPPC, in conjunction with Council staff, puts together a legislative platform on a yearly basis. This platform targets policy-level changes that will also identify and drive specific activities.

The Council uses a number of metrics to determine the overall success of goals, objectives and work plan activities. Because goals are broadly specific, their overall success is measured by meeting the more specific requirements of the objectives. Achievement of objectives involves the development, implementation and measurements associated with SCDD's annual work plans. The Council (through its regional staff) develops its work plan on an annual basis, projecting the number of activities planned and the number of people to be reached. Individuals with I/DD, their families and others are then surveyed to determine more specific satisfaction levels, involvement in advocacy and governance efforts, and an array of demographics to identify those participating and their responses to the Council's activities.

For people who have more specific questions, requests for assistance, etc., regional staff provides technical assistance (TA) on an as-needed basis, which may include TA clinics. Technical assistance may be provided by phone, email, in-person clinics, or via virtual,

online access, depending on the needs of the public and the constraints of the current public health crisis.

Finally, the Council produces an annual Program Performance Report (due each year by or prior to December 31st), which details the work of the Council and its significant findings. On (or before) January 1st of each year, the Council also submits its State Plan Update (SPU), which will detail any changes (at the objective level) that the Council will be making, over the course of the next federal fiscal year (FFY). If the Council identifies changes that need to be made to any State Plan goals, those changes 1) will be made subject to a 45-day public comment period and 2) must be submitted (as a State Plan Amendment [SPA]) to the federal government (Administration on Community Living [ACL]) by August 15th for federal approval/acceptance, prior to submission of the end-of-year PPR and SPU.

As to the choice of partners in Objective 2.3, the federal government requires the Council's 5-year State Plan to include an objective with a project that will combine the work of the Council, Disability Rights California (DRC), and all three (3) University Centers for Excellence in Developmental Disabilities (UCEDD) (USC Tarjan Center, UCLA Children's Hospital and UCD Mind Institute). The Council and its four (4) federal partners (which are all agency members on the Council) receive funds from the federal government to work both together and as separate agencies on projects that will help people with intellectual/developmental disabilities and their families. While these federal partners are specifically identified in the objective language, the Council is not limited to working with those agencies alone. In fact, SCDD typically engages in other collaborative relationships with every goal and objective, as well as at the individual activity level.

Staff Recommendation (Goal 2)

The responses (for Goal 2) submitted during the public comment period addressed questions or concerns that: 1) are already part of the proposed 2022-26 State Plan, or 2) may be integrated into annual work plans throughout the course of the 5-year State Plan period.

At this time, staff is making no recommendations for changes in Goal 2 of the proposed 2022-26 State Plan (as written).

Goal 3 (including 3 objectives):

The Council will partner with and empower more people with intellectual/developmental disabilities and their families, so they know their rights and can advocate for and receive supports and services

Of the 46 responses that the Council received in response to its survey, five (5) responses reflected positive approval; fourteen (14) comments provided a combination of positive feedback, questions, suggestions, etc. (with an additional request for money); seven (7) comments provided critical feedback; and 24 comment sections were left blank.

GREAT JOB!!!!

I can't thank you enough! That's amazing!

Yes, I totally agree with these goals.

We support this goal and these objectives, and want to add some detail to consider within this goal...

Live this goal!

Survey Responses (Goal 3):

Of the fourteen (14) comments providing a combination of positive feedback, questions and suggestions, the following responses were noted:

- A.** Respondents requested that the Council concentrate on specific topic areas, such as:
 - 1)** Education
 - 2)** Self-Determination
 - 3)** Transition
 - 4)** Employment
 - 5)** Regional Center and/or other available services
 - 6)** Reimbursement of legal fees (for parents/clients) in cases involving regional centers
- B.** Observations regarding different capacity/ability levels in people with intellectual/developmental disabilities
- C.** Requests to expand the target population of the disparities-related objective (Objective 3.3) to include other underserved populations (e.g. African-American/Black, etc.)
- D.** A question regarding the measurability (and associated metrics) of goal progress

E. A request provided suggestions about (potential) collaborative partners in the Council's work (in the provision of specific therapeutic models)

- 1.** Education is paramount for students and their families. Students need education so that they can grow and have opportunities to settle down and have a solid career that they can focus on and grow from.
- 2.** Focus on self-determination and transition. At least in the ACRC area, self determination is under utilized even for those approved. Transition services are modeled entirely too closely to high school and aren't preparing students and their families for adulthood- jobs don't always happen during school hours, for example.
- 3.** Employment will help so many self-advocates
- 4.** Employment remains a big deal and a big barrier in this community. Tackle that!
- 5.** A fee provision should be added, such as the provision in IDEA. If a family member/consumer/caretaker needs to obtain a lawyer to receive needed services from regional center, then regional center is responsible for paying for the attorney's fees if the claims are valid; See: <https://sites.ed.gov/idea/regs/b/e/300.517>. This will facilitate better and more effective advocacy on behalf of consumers.
- 6.** The State Council could add an objective to offer many more trainings to individuals about the various critical services available through various Regional Centers across the state for children over the age of 3. They are often told by their service coordinators that after the age of 3, all services are provided through the school district. Families need trainings so that they know they are able to advocate for and increase the type/quality of needed home-based services for themselves or their children/adolescents at their local Regional Centers.
- 7.** This objective seems limited considering Spanish speaking students are only one group of students with intellectual and developmental disabilities. There should be a 4th objective added to address the needs of CA students with disabilities, especially since Black students with disabilities are the lowest performing group of students with disabilities.
- 8.** ARCA supports the Council's plan to reduce disparities in obtaining a free, appropriate public education. ARCA believes that understanding and honoring the diverse cultures of people with developmental disabilities and their families is important to reducing disparities within the education system. ARCA recommends the Council go beyond working with Spanish-speaking families/self-advocates and seek to reach a variety of diverse communities in its work in this area. ARCA also recommends SCDD consider hosting focus groups to understand how families expect education to be delivered.
- 9.** I am glad the Hispanic community will be getting the attention and support it has been missing in part due to disparity. I think the idea of self-advocacy has to start

with the very young. We need to raise confident, healthy (at least as far as their medical conditions allow) self-advocates from infancy. I think the problems of adult self-advocates who did not receive the appropriate and adequate nurturing, education and opportunities across time would have more sophisticated issues than those who have had sufficient intervention since infancy. On the other hand, self-advocates who had the exposure to education approximating their age level would likely present more advanced needs.

- 10.** Again, how do we measure progress for this goal? For Objective 1, how many many people did SCDD provide training to so that we know whether providing training to 60,000 is an increase and by how much? For Objective 2, how many projects and events did SCDD provide so that we know whether providing 100 projects and events is an increase and by how much? For Objective 3, how many Spanish-speaking families did SCDD provide training to so that we know whether providing training to 5000 Spanish-speaking families is an increase and by how much?
- 11.** What comes to mind with this initiative are the words of Jesus Christ, "Whatsoever you do to the least of My people, you do to Me." It is definitely a move towards righteousness that we level the disparity among all the racial groups because it is simply not just. We are all human, therefore all made in the image and likeness of Our God. We are all children of God, therefore God lives in each one of us and we are rightfully treated with the dignity of a child of God, regardless of color, race, language, disability or intellectual ability or appearance because God has made all of us equal. You have talents that I may have but some abilities that I do not have. I may have talents that you may have but other abilities that you do not have. God has leveled the playing field long before each one was born so discovering the ways in which we can derive the specific super-talent that each one has is the task of the leadership of the people who are in charge of taking care of persons with disabilities. Hopefully we can harness the goodness of each one of us, with disabilities or not. "
- 12.** We want to emphasize how use of the DIR/Floortime Model (and other DRBIs - Developmental Relationship Based Interventions) supports self advocacy by helping people with developmental challenges to assert themselves vs more common behavioral approaches that aim to have the person meet goals decided for them without taking their perspectives into account. California has a wealth of providers trained and skilled in this proven method throughout the state. Several of us would be willing to provide more information or training to whomever about the use of this wholistic and person-centered approach. Some additional information can be found at www.dirfloortimecoalition.com, for example. More knowledge/awareness and/or use of this approach more widely might help improve outcomes related to these objectives.
- 13.** Sometimes, self-advocacy and/or the support of an armchair advocate is insufficient. Sometimes professional advocates and/or attorneys must be hired. The Regional

Center should pay for this expense. If not, it effectively prevents parents/consumers from advocating for themselves when things get very heated and/or complicated.

14. What is the timeline to meet this goal?

In respondents' critical responses, there was one comment made about the term 'technical assistance' being unclear. The remaining comments expressed concern about the Council's choice of the Spanish-speaking population as the focus for the disparity objective's project, as opposed to other underserved populations (e.g. other non-native, non-English speakers, Asians, Armenians, etc.), in addition to questions regarding measurability.

- 1.** 'Objective 1: technical assistance' does not have context; it reads more like providing tech support for the virtual trainings.
- 2.** Objective 3: Why only Spanish? This seems very discriminatory. Please widen the breadth of this to all non-native English speakers!"
- 3.** How does this goal relate to the Deaf community? The word "deaf" does not appear in the State Plan.
- 4.** What about the other linguistic groups represented? In the Southern California area you have a large Armenian population, In the North State area Asians comprise a large group. I worry that the cultural needs of these various groups may be neglected.
- 5.** This objective seems limited considering Spanish speaking students are only one group of students with intellectual and developmental disabilities. There should be a 4th objective added to address the needs of CA students with disabilities, especially since Black students with disabilities are the lowest performing group of students with disabilities.
- 6.** Again, how do we measure progress for this goal? For Objective 1, how many many people did SCDD provide training to so that we know whether providing training to 60,000 is an increase and by how much? For Objective 2, how many projects and events did SCDD provide so that we know whether providing 100 projects and events is an increase and by how much? For Objective 3, how many Spanish-speaking families did SCDD provide training to so that we know whether providing training to 5000 Spanish-speaking families is an increase and by how much?
- 7.** How will you make sure that you are reaching different individuals instead of counting the same person over and over again? How come you are working with only Spanish speaking families? People speak so many languages in CA.

Analysis/Response (Goal 3): Observations/Questions/Suggestions and Critical Feedback

Goal 3 is the section of the Council's designated plan to provide general capacity-building/advocacy activities.

Six (6) observations/suggestions requested that the Council address needs in specific, identified subject matter areas (e.g. employment, self-determination, etc.). Self-determination is an issue that will be addressed within the 5-year State Plan. For a complete response to the issue of legal fee reimbursements (regarding disputes with the regional center[s]), please see the analysis for Goal 2.

Training, information, resources, technical assistance, etc. are included within the objective language of this goal and will be further described in annual work plans for each of the five (5) years of the proposed 2022-26 State Plan. There is no restriction identified, regarding training, which is completely consistent with the Council's State Plan work. For decades, the Council has been aware of and responsive to the regional and statewide needs of people with disabilities and their families, largely through outreach and advocacy efforts. As needs arise, SCDD's personnel respond with technical assistance, training, and other activities designed to educate and empower family and self-advocates and others. Goal 3 is designed to provide training in any area of need for people with intellectual/developmental and/or cross-disabilities (and family members) throughout the state.

The suggestion regarding potential partnership and specific therapeutic interventions is one that was also made in response to the first two (2) goals. For more information in response to that suggestion, please refer to the analysis of public comments about Goal 1.

Three (3) comments expressed concern about the Council identifying Spanish-speaking family/self-advocates as the focus of a targeted disparity project (Objective 3.3). As mandated by the Administration on Community Living (ACL), the Council is required to identify one (1) specific, underserved population for a disparity-related project/objective.

NOTE: Please note that the Council's current (2017-21) 5-year State Plan also contains an objective (Objective 6.1) with a targeted disparity project, as federally required. While the Council extended the targeted population within the work of Objective 6.1 to include an Asian language-speaking population, it was only after completing the primary work to provide Spanish translations for regional center purchase-of-service terms that the Council was able to expand its focus to other languages. It will continue to expand this work in order to reach as many non-English-speaking populations as possible over the next few months/years.

In response to the Council's statewide survey (used to identify areas of need throughout the state for people with intellectual and/or developmental disabilities and their families), Spanish was the language in which SCDD received (by far) the most responses. Staff identified the most pressing concern expressed by Spanish-speaking family/self-advocates

was knowing about and obtaining services through the school system. Because of the sheer volume of similar responses (in Spanish), the State Plan Committee made the decision to focus on increasing free, appropriate public education (FAPE) and special education services for people in Spanish-speaking populations throughout the state. Through Objectives 3.1 and 3.2, the Council will continue to engage in training, outreach and special projects to serve all people with intellectual and/or developmental disabilities and their families throughout the state in obtaining necessary supports and services. For the purpose of the disparity project, however, only one (1) underserved population (that of those speaking primarily Spanish) has been chosen.

The Council received comments pointing out the differing levels of ability in people with intellectual and/or developmental disabilities. The Council acknowledges that everyone has different abilities and works to ensure that its training, outreach, information, resources and online material meets the needs of everyone, regardless of ability.

The Council again received a public comment about its ability to measure and report progress about Goal 3. For an extensive explanation about SCDD's data measurement and reporting, please see the analysis section for Goal 2. A comment was also made about the goal timeline, which has already been discussed.

Most of the critical public comments about Goal 3 addressed expanding the focus of Goal 3 beyond just Spanish-speaking populations, which has already been addressed. Another comment again raised the question of including mention of the deaf community, which has also been addressed (in the Goal 1 analysis section). A final comment questioned the meaning/purpose of 'technical assistance.' In the case of the Council's work, technical assistance is the provision of answers to questions, technical information about service/support systems, referrals, etc. for people with very specific questions and/or problems/issues. Technical assistance is often provided in response to telephone inquiries, community outreach events (e.g. resource fairs, conferences, etc.), trainings, clinics, etc. Council staff is always available and willing to help with information, answers and referrals to public inquiries and requests for assistance, although staff is not authorized to provide direct representation (e.g. advocacy during IEPs, etc.) or personal services.

Staff Recommendation (Goal 3)

The responses (for Goal 3) submitted during the public comment period addressed questions or concerns that: 1) are already part of the proposed 2022-26 State Plan, or 2) may be integrated into annual work plans throughout the course of the 5-year State Plan period.

At this time, staff is making no recommendations for changes in Goal 3 of the proposed 2022-26 State Plan (as written).

Conclusion:

The Council received surveys from 46 individuals, although fifteen (15) of those responses were completely blank and an additional survey was entered strictly as a request for money.

- 17 comments were positive/approving
- 49 comments were neutral observations or included questions/suggestions
- 14 comments contained critical observations, questions or requests

There were no comments provided through the Public Comment Period that required substantive changes to the either the intent or the language of the California State Council on Developmental Disabilities' proposed 2022-26 State Plan. All of the requests that were made (via public comment) are already part of the Council's mission, policies or practices and/or may be integrated into its annual work plans. Furthermore, the proposed State Plan meets federally mandated requirements, in regard to partnerships, projects, and targeted populations.

Proposed 2022-26 State Plan: Staff Recommendation

At this time, staff recommends that the State Plan Committee approve its proposed 2022-26 State Plan, as written and (previously) submitted to the full Council.

References

California Department of Developmental Services (DDS) (2020). *Quarterly Consumer Characteristics Report Index* (September 2020). Transparency: *Facts & Stats* (10.12.20)1-55, Tables 1-52. Data compiled from CDER Master File of Thursday, 10.1.1020; report issued on 10.12.20. Retrieved on 10.21.20:1430 from <https://www.dds.ca.gov/transparency/facts-stats/quarterly-client-characteristics-reports/>.