

EXECUTIVE SUMMARY
Culturally and Linguistically Competent Self-Determination Program
for Communities Traditionally Favoring Interdependence
DDS SAE Grant # 20-C34
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Project summary

A statewide Self-Determination Program (SDP) is mandated by California Welfare and Institutions Code, Division 4.5, Chapter 6, Article 4, Section 4685.8 to be “available in every regional center catchment area to provide participants and their families, within an individual budget, increased flexibility and choice, and greater control over decisions, resources, and needed and desired services and supports to implement their IPP.” Because the SDP pilot, and the subsequent SDP roll-out in July 2021 have revealed barriers to families’ participation, culturally and linguistically - tailored needs assessment of families from diverse backgrounds is necessary to ensure equitable access to the program. To this end, the project team collected and analyzed a substantial corpus of focus group data to understand African American / Black including Ethiopian and Eritrean, Chinese, and Latino families’ perceptions and experiences of SDP as actual or potential participants. The project’s geographical area is Los Angeles County. An additional content area was to document Self-Advocates’ experiences and perceptions of SDP. Based upon our findings, we developed a set of recommendations to help improve system-level cultural responsiveness of the SDP outreach and implementation.

Community Partners

The project was carried out by a team from the USC University Center for Excellence in Developmental Disabilities at Children’s Hospital Los Angeles in partnership with three Community Based Organizations that each contributed technical expertise, and linguistic and cultural knowledge of their respective communities:

- **Leap of Faith Family-To- Family Support (Felicia Ford, Executive Director and Founder)** creates opportunities for socialization and wellness for people with developmental disabilities and their families through culturally compatible, supportive, and inclusive events. The mission of Leap of Faith is to advocate for racial equity and for empowering African-American/Black families’ voices in speaking up and addressing their concerns regarding systemic issues leading to purchase of services (POS) disparities. Leap of Faith serves all individuals and their families receiving regional center services, with an emphasis on African-American/Black clients and under-resourced populations in Southern California living in family home or community settings, and all developmentally disabled and dually diagnosed individuals and their families. Felicia Ford has brought to the project her experience of successful implementation of the SDP in her own family, and her expertise as a member of the Westside Regional Center’s SDP advisory board.

- **Chinese Parent Association for the Disabled (CPAD)** is a non-profit organization dedicated to helping individuals with developmental disabilities and special needs, and their families. All the CPAD’s parent members are volunteers, and strive to help each individual achieve his or her full potential toward a meaningful and productive life. Through its many social activities and community events, CPAD creates opportunities for social integration and social inclusion into mainstream society. On a weekly basis, CPAD provides educational and recreational services specifically designed for member’s children with special needs. CPAD’s parent trainings and social activities are held at local facilities and specifically target the Cantonese and Mandarin speaking community. CPAD has served as a

Community Parent Resource Center (CPRC) in partnership with Fiesta Educativa since 2004. The two organizations have collaborated on other projects including The Family Mentor Partner Program: Valuing and Connecting Hispanic and Chinese Families with Regional Center services funded by the DDS Service Access and Equity program in the FY 2017/2018.

-Fiesta Educativa Inc. is a private non-profit, 501 (c) (3) organization whose mission is to address the special needs of Latino families with members who have disabilities. It accomplishes this through education, training, information, and advocacy. It is committed to assisting persons with special needs in becoming productive and independent members of their communities. Fiesta Educativa, Inc. was founded in 1978 as a private non-profit corporation with the mission to address the special needs of Latino families, primarily Mexican/Mexican American families whose members have disabilities. Its impressive record of service has placed Fiesta Educativa among the leading disability advocacy organizations working on behalf of Latinos in California and nationally. Fiesta Educativa serves adults, children and infants with disabilities, emphasizing the provision of services in the home to reduce cultural obstacles and improve access to service delivery.

Methodology

We used a qualitative methodology that is commonly utilized for analysis of perceptions, beliefs and experiences related to a topic. Specifically, the focus group methodology allows to gather rich experiential data to identify preferences and clarify choices in a time-efficient and culturally responsive way. The CBO leaders were trained by project staff to conduct focus groups to ensure that the groups were led by trusted facilitators, and that the participants had the opportunity to openly share their thoughts and experiences in their preferred languages or dialects.

Data collection had the following elements:

- **Creating a ‘safe space’ for an open conversation:** the focus groups provided a social context in which the participants were comfortable sharing their experiences in their preferred language
- **Rethinking what constitutes a ‘group’ in ‘focus group’:** due to cultural preferences of some participants, family members were interviewed together rather than in a group with unfamiliar people
- **Focus group facilitators** were trusted community insiders who spoke the participants’ language, and understood their cultural preferences

In total, **19 focus groups** were conducted remotely via zoom:

- **Chinese Parents Association for the Disabled (CPAD)** conducted 6 focus groups for Chinese parents and siblings (1 in Cantonese; 5 in Mandarin)
- **Leap of Faith Family to Family Support** conducted 5 focus groups for Black / African American parents and self-advocates; and facilitated 2 focus groups for Ethiopian / Eritrean parents in Amharic
- **Fiesta Educativa** conducted 5 focus groups for Latino families in Spanish; and facilitated 1 focus group for Self-Advocates in English

Data analysis

All focus groups were video-recorded. Thematic analysis of focus group transcripts and summaries was carried out using NVivo software. (<https://www.qsrinternational.com/>).

Data analysis generated 174 themes that were cross-referenced and aggregated across all focus groups within each community. Shared themes were identified that carried across the participants' communities.

Through an iterative coding process, the themes were grouped into **4 major content areas**:

- SDP Advantages and Disadvantages (program - level)
- SDP Challenges and Strategies (system - level)

A summary of thematic analysis is provided in the tables below.

Table 1: SDP Advantages

SDP Advantages: Themes	African American / Black parents	Ethiopian / Eritrean parents	Latino parents	Chinese parents and siblings	Self-Advocates
Freedom of Choice for					
- An Independent Facilitator	✓	✓		✓	✓
- SDP team	✓				✓
- Programs and providers	✓	✓	✓	✓	✓
- Culturally-responsive / relevant services	✓	✓	✓	✓	
- Working with people from one's community	✓	✓	✓	✓	
- Geographical area where the programs / providers are located	✓			✓	
Flexibility and Control					
- To change services	✓				
- To change an Independent Facilitator	✓				✓
-To receive services previously denied or that are unavailable in the traditional service model	✓	✓	✓	✓	✓
- WHO WHEN WHERE and HOW of services	✓				

- To reduce provider / staff turn-over	✓				
- To maximize expenditure of authorized services	✓				
- To have funding to support medical and recreational needs				✓	
-To get services faster, reduce wait time				✓	
- Educating and helping other people / families entering SDP	✓				✓
Person-Centeredness					
- Getting help with making our own plans and goals			✓		
- Catering to unique needs	✓		✓	✓	✓
- Building an identity, learning who we / our children are	✓				
- Strength-based, supporting hope, 'anything is possible'	✓				
- Creating a program that really works	✓		✓		
- Learning new skills such as using a computer, budgeting					✓
- To improve quality of life	✓				

Summary of themes reflected in Table 1:

SDP Advantages (program level)

Freedom of choice for

- *Independent Facilitator* (African American / Black parents, Ethiopian / Eritrean parents, Chinese parents and siblings, and Self-Advocates)
- *SDP team* (African American / Black parents, and Self-Advocates)
- *Programs and Providers* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings, and Self-Advocates)
- *Culturally - responsive, culturally - relevant services and Working with people from one's community* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings)

- *Geographical area where the programs / providers are located* (African American / Black parents, Chinese parents and siblings)

Flexibility and control

- *To change services* (African American / Black parents, Chinese parents and siblings)
- *To change the Independent Facilitator* (African American / Black parents, and Self-Advocates)
- *To receive services previously denied or that are unavailable in the traditional service model* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings, and Self-Advocates)
- *To educate and help other people / families entering SDP* (African American / Black parents, and Self-Advocates)
- *WHO WHEN WHERE and HOW of services; To reduce provider / staff turn-over; To maximize expenditure of authorized services* (African American / Black parents)
- *To have funding to support medical and recreational needs and To get services faster, reduce wait time* (Chinese parents and siblings)

Person-Centeredness

- *Getting help with making our own plans and goal* (Latino parents)
- *Catering to our / our child's unique needs* (Latino parents, Chinese parents and siblings, and Self-Advocates)
- *Building an identity, learning who we / our children are; Strength-based, supporting hope, 'anything is possible'; To improve quality of life* (African American / Black parents)
- *Creating a program that really works* (African American / Black parents, Latino parents)
- *Learning new skills such as using a computer, budgeting* (Self-Advocates)

SDP Disadvantages (program level)

Workload concerns

- *Parents take on an additional workload so their children can participate in SDP* (African American / Black parents)
- *Identifying and hiring the right providers is difficult and time-consuming* (Chinese parents and siblings)
- *Managing the budget and making decisions about services* (Latino parents)

SDP Challenges (system level)

Inequities of traditional service model carry over into SDP

- *SDP reveals socio-economic and racial / ethnic inequities in services and access to information about SDP ; Access to information about SDP depends upon one's social network* (African American / Black parents)
- *Understanding and accessing traditional service model is a pre-requisite / pre-condition for successfully using SDP*
(African American, Latino, Chinese parents and siblings)
- *Lack of trust in the regional center system leads to lack of trust in SDP* (African American parents, Chinese parents and siblings)
- *'Denial by delay': the process is so lengthy that families give up* (African American / Black parents)
- *Families' vision and hope have not been supported and some families have given up hope and are not seeking more support*
(Chinese parents and siblings)
- *The freedom to get services in SDP turned out to be limited; Families continue to be afraid to ask for services in SDP; Limited outreach of Regional Centers to Communities of Color leads to limited knowledge about SDP* (African American / Black parents)

Lack of access to usable information

- *Information about SDP is difficult to obtain* (African American parents, Chinese parents and siblings)
- *Information is difficult to understand* (African American, Chinese parents and siblings)
- *Parents learn about SDP from other parents rather than from the Regional Centers* (African American parents)
- *Lack of materials and e-mail communication in our language* (Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings)
- *Materials that are in our language are hard to understand due to low quality of translation and use of technical language*
(Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings)
- *Parents do not have information on how to enroll in SDP* (Latino parents)

Workforce

- *Lack of providers and programs available for SDP* (African American / Black, Ethiopian / Eritrean parents, Chinese parents and siblings)
- *Lack of providers who speak our language and understand our culture* (Ethiopian / Eritrean parents, Chinese parents and siblings)
- *Rates: Budget insufficient to hire providers who have higher rates than those vendored by Regional Centers*
- *Lack of experienced Independent Facilitators* (Chinese parents and siblings)
- *Lack of Independent Facilitators who speak our language* (Ethiopian / Eritrean parents, Chinese parents and siblings)

Support

- *Limited support for learning how to budget for SDP services* (Latino parents, Chinese parents and siblings, Self-Advocates)
- *Limited support for families enrolling in SDP* (Latino parents)

Enrollment

- *Enrollments requires multiple lengthy steps and many meetings* (Ethiopian / Eritrean parents, Chinese parents and siblings)
- *There are too many forms* (Latino parents)
- *Service Coordinators are not providing information or discouraging families to enroll in SDP* (Ethiopian parents, Latino parents, Chinese parents and siblings)
- *Concerns about interruption of services when enrolling in SDP* (Ethiopian / Eritrean parents)

Cultural barriers:

- *Reluctance to voice our needs proactively; Preference for privacy regarding family members situation and needs; Preference to be offered / recommended services rather than asking for services; Would like to see others in our community succeed in SDP before starting ourselves* (Ethiopian / Eritrean parents, Chinese parents and siblings)

SDP Strategies (system level)

Table 2: SDP Strategies: Making information accessible

SDP STRATEGIES: Themes	African American / Black parents	Ethiopian / Eritrean parents	Latino parents	Chinese parents and siblings	Self-advocates
Making information accessible					
- Glossary of terms	✓	✓	✓	✓	
- Use simple plain language	✓	✓	✓	✓	✓
- Use SCDD's information for Self-Advocates in plain language			✓		✓
- More outreach to Self-Advocacy groups			✓		✓
- Break down information into manageable bits, cover SDP step-by-step	✓	✓	✓	✓	
- Create a multi-lingual hotline for SDP				✓	
- Create multi-lingual social media informationals on YouTube and WeChat				✓	
- Create a multilingual handbook				✓	
- Present information and training in our language		✓	✓	✓	
- Have a community insider to present information about SDP		✓		✓	
- Have information and materials presented in our language(s)		✓		✓	

Summary of themes reflected in Table 2:

Making information accessible

- *Glossary of terms; Break down information into manageable bits, cover SDP step-by-step* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings)
- *Use simple plain language* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings, Self-Advocates)
- *Use SCDD's information for Self-Advocates in plain language; More outreach to Self-Advocacy groups* (Latino parents, Self-Advocates)
- *Create a multi-lingual hotline for SDP; Create multi-lingual social media informationals on YouTube and WeChat; Create a multilingual handbook* (Chinese parents and siblings)
- *Present information, training, and materials in our language* (Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings)
- *Have a community insider to present information about SDP* (Ethiopian / Eritrean parents, Chinese parents and siblings)

Table 3: SDP Strategies: Improvement of SDP implementation

SDP STRATEGIES: Themes	African American / Black parents	Ethiopian / Eritrean parents	Latino parents	Chinese parents and siblings	Self-advocates
Improvement of SDP implementation					
DDS needs to develop best practices for SDP	✓				
RCs need clear directives for working on SDP budgets	✓				
Mailing the SDP package directly to families and have a Regional Center staff member walk them through filling out the packet	✓				
Develop a support network in our community	✓	✓	✓		
Increase training for Service Coordinators about SDP and how to provide information	✓	✓	✓	✓	✓
Make enrollment shorter and more time efficient				✓	

Summary of themes reflected in Table 3:

Improvement of SDP implementation

- *DDS needs to develop best practices for SDP*
- *Regional Centers need clear directives for working on SDP budgets*
- *Mailing the SDP package directly to families and have a Regional Center staff member walk them through filling out the packet* (African American / Black parents)
- *Develop a support network in our community* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents)
- *Increase training for Service Coordinators about SDP on how to provide information* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings, and Self-Advocates)
- *Make enrollment shorter and more time efficient* (Latino parents)

Table 4: SDP Strategies: Increase SDP training for families and self-advocates

SDP STRATEGIES: Themes	African American / Black parents	Ethiopian / Eritrean parents	Latino parents	Chinese parents and siblings	Self-advocates
Increase SDP training for families and self-advocates					
Provide recordings of zoom information sessions	✓				
Organize SDP training courses and support groups for parents and Self-Advocates	✓				
Schedule trainings after hours so participants don't have to take time off work	✓	✓	✓	✓	✓
Make Regional Centers' SDP advisory board meetings open to the public	✓				
Develop a SDP training for Self-Advocates				✓	✓

Have those successful in SDP share their experiences and lessons learned				✓	
Develop training on planning and budgeting for services			✓	✓	✓
Organize training in a sequential, step-by-stem progression	✓	✓	✓	✓	✓

Summary of themes reflected in Table 4:

Increase SDP training for families and self-advocates

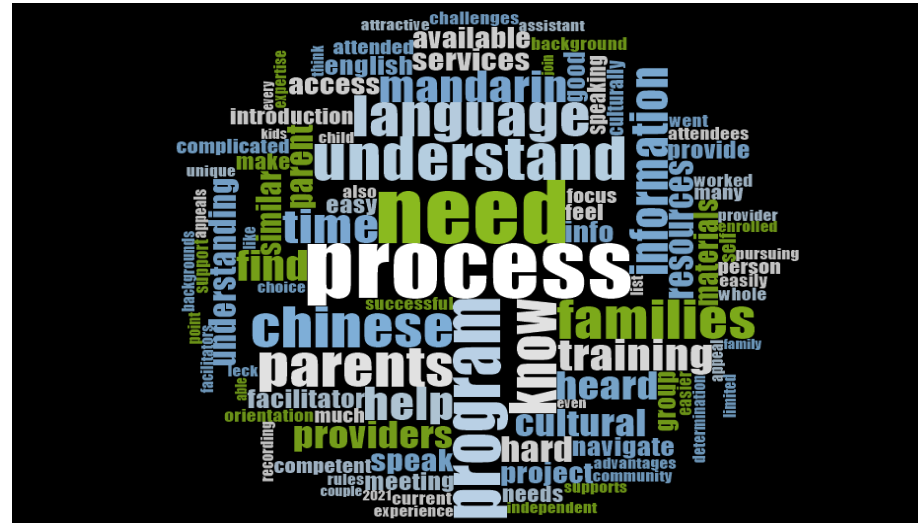
- *Organize training in a sequential, step-by-stem progression*
- *Schedule trainings after hours so participants don't have to miss work* (African American / Black parents, Ethiopian / Eritrean parents, Latino parents, Chinese parents and siblings, and Self-Advocates)
- *Provide recordings of zoom information sessions*
- *Organize SDP training courses and support groups for parents and Self-Advocate* (African American / Black parents; Self-Advocates)
- Have those successful in SDP share their experiences and lessons learned (Latino parents)

Table 5: SDP Strategies: Increase workforce diversity

SDP STRATEGIES: Themes	African American / Black parents	Ethiopian / Eritrean parents	Latino parents	Chinese parents and siblings	Self-advocates
Increase workforce diversity					
Increase the pool of Independent Facilitators and other professionals from our community to increase racial / ethnic / cultural / linguistic concordance	✓	✓		✓	
Independent Facilitators must know the Regional Center system and the services in the traditional model	✓	✓	✓	✓	✓



Wordcloud for the Chinese parents and siblings' Focus Groups



Wordcloud for the Self-Advocates' Focus Groups



Conclusions and Recommendations:

The participants formulated strategies that serve as **a roadmap for SDP quality improvement and systemic change.**

They had a candid conversation in a 'safe space' created by the focus group facilitators where they shared their experiences with openness and vulnerability.

Consistent with the preferences for interdependence of their cultural groups, the participants often spoke from a collective perspective of '*we, us, ours*' rather than from an individualistic perspective of '*I, me, and mine*'.

Some themes were unique to the groups while others were cross-cutting across some or all the groups.

The Self-Advocates' focus group formulated a distinct set of advantages, disadvantages, challenges, and strategies.

The themes across several or all groups that may be applicable to other cultural groups:

The themes with greatest frequencies:

Challenges:

- Not having enough information, or information is unclear or withheld
- Lack of Independent Facilitators who speak our language and understand our culture
- Lack of information in our language
- Lack of materials and e-mail communications from RCs in our language

Advantages:

- Freedom of choice to select services and providers who are more appropriate
- Having flexibility and control of services WHO WHEN WHERE and HOW

Strategies:

- Cultural concordance with people who are part of the SDP team
- Train Service Coordinators in SDP terms and how to provide information

The most cross-cutting themes:

Advantages:

- Freedom of choice for programs and providers
- Culturally-responsive / culturally-relevant services
- Working with people from one's community
- Flexibility and control to receive services previously denied or that are unavailable in the traditional service model
- Person-centeredness: catering to our / our children's unique needs

Challenges:

- Understanding and accessing traditional service model is a pre-requisite / pre-condition for successfully using SDP
- Lack of materials and e-mail communication in our languages
- Materials that are in our languages are hard to understand due to low quality of translation and technical language
- Lack of providers and programs

Based upon the data analysis, the team recommends the following:

- Develop a glossary of terms for SDP
- Use simple / plain language in all target languages
- Provide all documents in high quality translation (especially with regards to technical terms)
- Have SDP informational events with simultaneous interpretation by interpreters familiar with the terminology of SDP in each language
- Break down information into manageable bits and cover SDP step-by-step
- Develop a support network for communities, in their languages, led by trusted messengers / cultural insiders
- Increase training for Service Coordinators about SDP on how to provide information
- Schedule trainings after hours so parents don't have to miss work
- Develop training on planning and budgeting for SDP services
- Organize training in a sequential, step-by-step progression
- Increase the pool of Independent Facilitators and other professionals to increase racial / ethnic / cultural / linguistic concordance
- Train Independent Facilitators in the regional center services in the traditional model
- Simplify the process of enrollment in SDP by reducing the number of meetings and forms to fill out
- Shorten the period of enrollment so families do not lose motivation and hope

APPENDIX 1: Suggested focus group questions

- What have you heard about SDP? What is your current understanding of SDP?
- What appeals to you about SDP? What doesn't appeal to you about SDP?
- Are there challenges to participation in SDP that are unique to families with cultural backgrounds similar to yours?
- Are there advantages in pursuing SDP for families with cultural backgrounds similar to yours?
- In your experience, is information about SDP easily available in your language of choice?
- Is information about SDP easy to access and understand?
- What supports do you know about (such as Independent Facilitators) to help you navigate the SD process?
- If you have worked with an Independent Facilitator, was that person culturally competent and / or did they speak the language(s) of your community?
- What would make the SDP process more attractive or easier to use?
- What expertise / training do you feel families need to be successful in SDP?

APPENDIX 2: SDP resources

- State-wide

California Department of Developmental Services

<https://www.dds.ca.gov/initiatives/sdp/>

<https://dds.ca.gov/initiatives/sdp/frequently-asked-questions/>

Disability Voices United

<https://disabilityvoicesunited.org/self-determination/>

State Council of Developmental Disabilities (SCDD) introduction to SDP

<https://scdd.ca.gov/wp-content/uploads/sites/33/2021/07/Introducing-the-Self-Determination-Program.pdf>

SCDD's SDP Facebook forum

<https://www.facebook.com/groups/CA.SDP.Forum>

California SDP Network (information provided in many languages)

<https://www.thecasdpnetwork.org/>

- Los Angeles County

Los Angeles County regional centers' SDP pages:

<https://sclarc.org/self-determination-program.php>

<https://westsiderc.org/self-determination-program/about-the-program/>

https://lanterman.org/selfdetermination/introduction-to-self-determination#.Yorr_6jMK5c

<https://www.elarc.org/consumers-families/self-determination>

<https://www.nlacrc.org/consumers-families/self-determination-program>

<https://www.harborrc.org/self-determination>

<https://www.sgprc.org/clients-families/self-determination-program>