



# NOTICE/AGENDA

## STATE COUNCIL ON DEVELOPMENTAL DISABILITIES SELF-ADVOCATES ADVISORY COMMITTEE MEETING

Members of the public may participate in person, or telephonically. Accessible formats of all agenda and materials can be found online at [www.scdd.ca.gov](http://www.scdd.ca.gov).

**PHYSICAL LOCATION:**

Holiday Inn, Sacramento Downtown,  
300 J St.  
Sacramento CA 95814

**TELECONFERENCE: (669) 900-9128**

**MEETING ID: 881 3267 4600**

**MEETING PASSWORD: 786648**

**DATE:** July 17, 2023

**TIME:** 2:00 P.M. to 4:30 P.M.

**COMMITTEE CHAIR:**

Nicole Adler

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**Item 1. CALL TO ORDER**

**Item 2. ESTABLISH QUORUM**

**Item 3. WELCOME AND INTRODUCTIONS**

#### **Item 4. PUBLIC COMMENTS**

This item is for members of the public only to provide comments and/or present information to the Committee on matters not on the agenda. Each person will be afforded up to 3 minutes to speak.

Additionally, there will be up to 5 minutes allocated to hear from the public on each agenda item, with each person allotted up to 1 minute to comment.

#### **Item 5. APPROVAL OF MAY 22, 2023 MINUTES**



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#### **Item 6. MEMBER UPDATES**

**Page 11**

- A. Updates/Concerns from Regional Advisory Committees
- B. Emerging Issues or Barriers to Self-Advocacy
- C. Community self-advocacy projects/activities
- D. SCDD Committee Updates
- E. Statewide Self-Advocacy Network (SSAN) Report
- F. Recommendations for Future Meetings and Projects

#### **Item 7. REVIEW OF COUNCIL BUSINESS**

Presented by: SCDD Executive Director Aaron Carruthers

- A. SCDD Agency Update
- B. Review of Council Agenda
- C. Developmental Center Update

**ITEMS RELATED TO COUNCIL BUSINESS ARE INCLUDED IN THE COUNCIL PACKET**

**Item 8. SELF-DETERMINATION PROGRAM EVALUATION  
RECOMMENDATION HIGHLIGHTS**

**Page 17**

Presented by: SCDD Staff

**Item 9. REFLECTIONS ON THE AMERICANS WITH DISABILITIES ACT  
AND NEXT STEPS**

**Page 35**

Presented by: SCDD Staff

**Item 10. ADJOURNMENT**

Next Meeting: September 18, 2023

**Accessibility**

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**All times indicated and the order of business are approximate and subject to change.**

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**JULY 17, 2023**  
**AGENDA ITEM 5**  
**ACTION ITEM**

**SELF-ADVOCATES ADVISORY COMMITTEE**  
**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

**Approval of May 22, 2023 Minutes**

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***Action Recommended***

Approve the May 22, 2023 SAAC Minutes

***Attachments***

- May 22, 2023 SAAC Minutes

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**SELF-ADVOCATES ADVISORY COMMITTEE MEETING MINUTES  
MAY 22, 2023**

**Members Present**

Nicole Adler (SA)  
Jeana Eriksen (SA)  
Julie Gaona (SA)  
Julio Garnica (SA)  
Sonia Jones (SA)  
Kara Ponton (SA)  
Rosanna Ryan (SA)  
Wesley Witherspoon (SA)  
Eric Ybarra (SA)

**Members Absent**

Alex Reyes (SA)  
Nester Nieves (SA)

**Others Attending**

Mozh Akbari  
Rihana Ahmad  
Haneef Akbari  
Renee Bauer  
Aaron Carruthers  
Michelle Cave  
Sofia Cervantes  
Janet Fernandez  
Dena Hernandez  
Riana Hardin  
Beth Hurn  
Marianne Iversen  
Stacy Martinez  
Charles Nguyen  
Lynn Villoria  
Tobias Weare

**1. CALL TO ORDER**

Committee Chair Nicole Adler called the meeting to order at 1:36 P.M.

**2. WELCOME AND INTRODUCTIONS**

Committee members and others in attendance introduced themselves.

**3. ESTABLISHMENT OF QUORUM**

A quorum was established.

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Legend:

SA = Self-Advocate

FA = Family Advocate

**4. PUBLIC COMMENT**

A public member, Marianne Iversen from the Downs Syndrome Connection of the Bay Area (DSCBA) stated that DSCBA is looking for self-advocates who are interested in working with them and talking with them about mental health best practices and resources. Anyone who is interested in helping can email Marianne Iversen at [Marianne@dscb.org](mailto:Marianne@dscb.org).

**5. APPROVAL OF MARCH 20, 2023 MINUTES**

Members reviewed the minutes from the March 20<sup>th</sup>, 2023 meeting. The minutes can be found starting on page 7 of the May 2023 SAAC packet.

**ACTION 1**

It was moved/seconded (Witherspoon [SA]/ Ybarra [SA]) and carried to approve the March 20<sup>th</sup> minutes as presented. (Aye: Adler [SA], Jeana Eriksen [SA], Gaona [SA], Garnica [SA], Ponton [SA], Ryan [SA], Witherspoon [SA], and Ybarra [SA]; Abstain: Jones [SA]; Not Present: Nieves [SA] and Reyes [SA]). Motion passed.

**6. MEMBER UPDATES**

Members shared issues of concern in their communities including the impact recent weather-related power outages had on self-advocates, access to services during emergency situations, access to mental health services, the need for affordable housing, the importance of privacy, and access to education, access to facilitation and personal care services, and low attendance at self-advocacy meetings.

**7. REVIEW OF COUNCIL BUSINESS**

SCDD Executive Director Aaron Carruthers provided members with an update on the status of the agency and an overview of the May Council meeting agenda. SCDD continues statewide efforts to promote access to supports and services for people with I/DD so they can be included in their communities. Executive Director Carruthers assured members that SCDD is monitoring federal developments on the debt ceiling.

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Legend:

SA = Self-Advocate

FA = Family Advocate



## **DRAFT**

### **8. SCDD TRAVEL TRAINING**

SCDD State Plan Analyst Beth Hurn provided an overview of the SCDD Travel Policy and process to prepare members for the upcoming in-person meetings in July. This training included information about the forms used to report travel related expenses, SCDD preferred transportation carriers, reimbursement rates for meals, and time frame for requesting travel.

### **9. LIVING IN CHANGING TIMES**

SCDD North Bay Community Program Specialist, Tobias Weare shared with members the North Bay Regional Office's efforts to reengage with self-advocates in Council Activities. The North Bay Regional Office has been retooling information from other regional office staff related to mental health to serve their communities.

Members shared their challenges with learning new technologies and adapting to changes due to public health concerns. Concerns were brought up about the high turnover rate of regional center staff due to the public health emergency and the high caseloads (number of clients staff are responsible for). There continues to be an inconsistency in the training for new hires.

Members talked about the challenges of being independent and stress related to managing their services and needs.

### **10. ADJOURNMENT**

The meeting was adjourned at 4:13 P.M.

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Legend:

SA = Self-Advocate

FA = Family Advocate

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**JULY 17, 2023**  
**AGENDA ITEM 6**  
**INFORMATION ITEM**

**SELF ADVOCATES ADVISORY COMMITTEE**  
**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

***Member Updates***

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Each member will have a chance to give the committee updates on local and regional concern(s) for people with intellectual and developmental disabilities (I/DD). Updates may include:

- A. Updates/Concerns from the Regional Advisory Committees (RAC)
- B. Emerging issues or barriers to self-advocacy
- C. Community self-advocacy projects/activities
- D. SCDD Committee Updates
- E. Statewide Self-Advocacy Network (SSAN) Report
- F. Recommendations for Future Meetings and Projects

**Attachments:**

- June 2023 Statewide Self-Advocacy Network (SSAN) Report

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**June 13, 2023**

**AGENDA ITEM 6 E.  
INFORMATION ITEM**

**SELF-ADVOCATES ADVISORY COMMITTEE**

***Summary of June 2023 Statewide Self-Advocacy Network Meeting***



**Recent Activity:** The Statewide Self-Advocacy Network (SSAN) met on June 7<sup>th</sup> and 8<sup>th</sup>, 2023 over Zoom.

**Focus of Meeting:**

The 2-day June 2023 SSAN meeting was held on Zoom. The meeting began with members holding a moment of silence to honor Judith Heumann, a disability rights icon who passed away recently.

Members opened the meeting by sharing their recent advocacy activities and what helps them when they are feeling overwhelmed. Members shared strategies like listening to music, talking to friends, going for walks, writing in journals, and meditating. Members also shared how having a disability has helped them to grow.

The meeting started with a presentation from the SSAN Vice-Chair and Secretary on the purpose of SSAN and the structure of the SSAN Workgroups. Member feedback on what SSAN could do better included recruiting new members and creating guidelines on full meeting and workgroup attendance. Members also agreed that there should be a process for tracking the presentations that SSAN members are providing in their communities.

The SSAN Operations workgroup talked about creating a medical/personal leave process to guide members when they need to miss multiple SSAN meetings. The SSAN Operations workgroup will work on drafting a policy/process for members to consider adopting.

Representatives from the Department of Developmental Services (DDS) provided an overview of the [DDS Coordinated Family Service \(CFS\)](#) program. CFS is tailored to individual and family needs and respects the language and culture of participants. CFS is designed to help participants to age in place with their families and community supports.

State Council on Developmental Disabilities (SCDD) Executive Director Aaron Carruthers updated members on SCDD activities since the March SSAN meeting. SCDD has released recommendations to end subminimum wage in California and continues to meet with DDS to discuss plans to phase out subminimum wage practices and promote competitive integrated employment (CIE) for people with I/DD by 2025. SCDD is recommending that a Statewide Employment First Office be created to help facilitate CIE implementation and serve as a connector between agencies advocating for employment of people with disabilities.

**June 13, 2023**

**AGENDA ITEM 6 E.  
INFORMATION ITEM**



**SELF-ADVOCATES ADVISORY COMMITTEE**

***Summary of June 2023 Statewide Self-Advocacy Network Meeting***

Day one ended with members discussing problems that people with disabilities face at work, including employers not recognizing their humanity, their value, their resiliency, and their adaptability.

Day 2 of the SSAN meeting started with members sharing their thoughts on what is missing from the Americans with Disabilities Act. Members mentioned the need for accessible bathrooms in all public buildings, agencies, stores, etc., equal marriage rights, and sexual health education for people with disabilities.

SCDD State Plan Analyst, Beth Hurn provided members with an overview of SCDD's Travel Policy. This training covered SCDD agency travel request procedures, current travel policies, and how to request travel reimbursements. Members should submit travel requests and reimbursement claims to [travelclaims@scdd.ca.gov](mailto:travelclaims@scdd.ca.gov).

SCDD Policy Analyst Veronica Bravo provided members with an update on SCDD's legislative activities, including SCDD's policy priorities, current legislative efforts, the current economic impact on the California Legislature and SCDD's efforts toward the implementation of SB 639.

The San Bernardino Regional SSAN Representative Eric Aguilar, provided members with a training on how to plan and prepare a survival kit in the case of an emergency. This training included a list of the types of items to include in your kit. Members wondered if there was a plan in place for how to respond to an emergency at an in-person SSAN meeting. Members expressed interest in a future SSAN emergency preparedness project.

**2022 – 2024 SSAN Leadership:**

**Chair:** Charles Nutt, North State Regional Representative

**Vice-Chair:** Nicole Patterson, DDS Representative

**Secretary:** Rebecca Donabed, Sequoia Regional Representative

**Actions Taken:**

- Approved the Minutes from the March 2023 SSAN Meeting
- Approved the June 2023 Edition of the SSAN Newsletter

The next SSAN Meeting will be held in-person in Sacramento in September. Be on the lookout for more details and visit the [SSAN Page](#) on the SCDD website for more information.

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**JULY 17, 2023**  
**AGENDA ITEM 7**  
**INFORMATION ITEM**

**SELF ADVOCATES ADVISORY COMMITTEE**  
**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

***Review of Council Business***

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State Council on Developmental Disabilities staff will review Council Business with the committee. This item may include:

- A. SCDD Agency Updates
- B. Review of Council Agenda items
- C. Developmental Center Updates

**Items related to this agenda item can be found in the Council Packet.**

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**JULY 17, 2023**

**AGENDA ITEM 8  
INFORMATION ITEM**

**SELF ADVOCATES ADVISORY COMMITTEE  
STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

***Self-Determination Program Evaluation Recommendation Highlights***

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One of the roles of the Self-Advocates Advisory Committee is to advise the Council on policies, programs and issues affecting self-advocates in California. Additionally, the committee advises the Council on plain language best practices.

SCDD Executive Director Aaron Carruthers will provide a high-level overview of the California Self-Determination Program Evaluation. The Self-Determination Program Evaluation lists 7 recommendations to address barriers to the program. The first recommendation is to improve access to information about Self-Determination Program.

This agenda item will provide members an opportunity to ask questions about the Self-Determination Program Evaluation and share their ideas on how to improve access to the program.

***Attachment***

Self-Determination Evaluation PowerPoint Presentation

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# Self-Determination Program (SDP) Evaluation

Aaron Carruthers, Executive Director

# Self-Determination Program (SDP) Evaluation

## June 2023

### Report:

SDP statutes requires this report, shall include:

- whether SDP is furthering the principles of the program
- recommendations to enhance the program's effectiveness
- Report may include participant satisfaction and other factors

### Partners

- State Council on Developmental Disabilities (lead)
- UCLA Tarjan Center for University Center for Excellence in Developmental Disabilities (data)
- Disability Rights California (collaborator)

### Findings Statement

- SDP furthers SDP principles
- People experienced with SDP largely view the program favorably and would recommend it to others, even with the barriers they describe
- Participants believe in SDP's concept and principles, but identify administrative burdens

# Program Evaluation Phases

N = 604

## Phase 1 (P1)

### Quantitative Survey

- Distributed late 2022
- 242 respondents

## Phase 2 (P2)

### Virtual Focus Groups

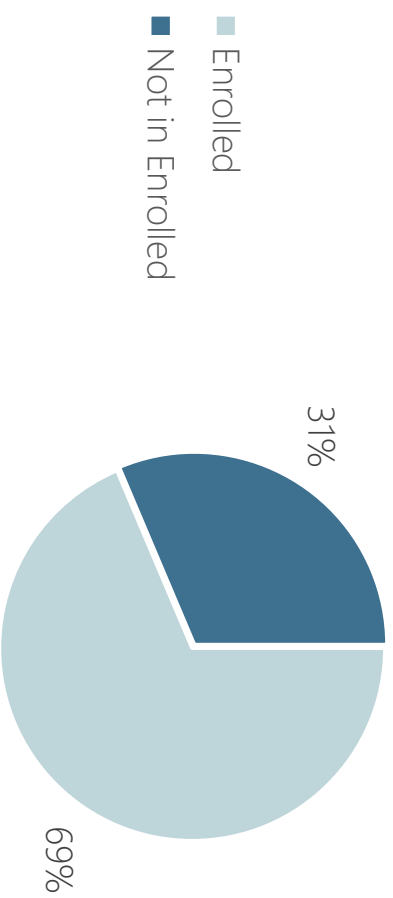
- April 2023
- 97 participants

## Phase 3 (P3)

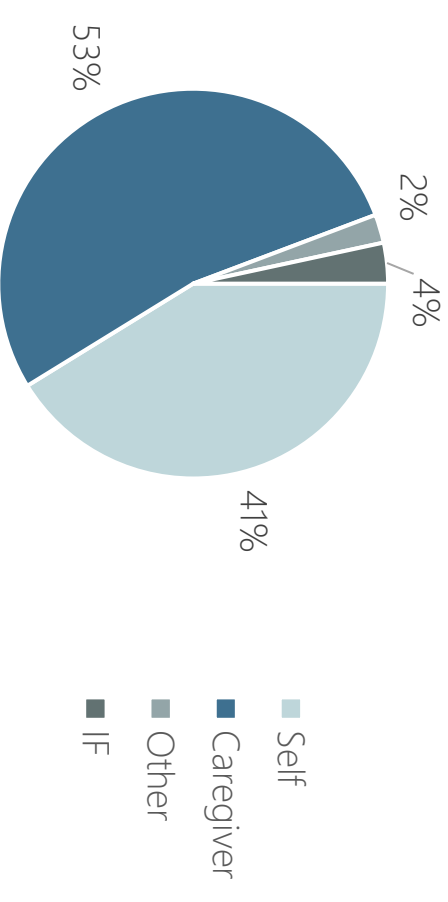
### Qualitative Survey

- May 2023
- 265 respondents

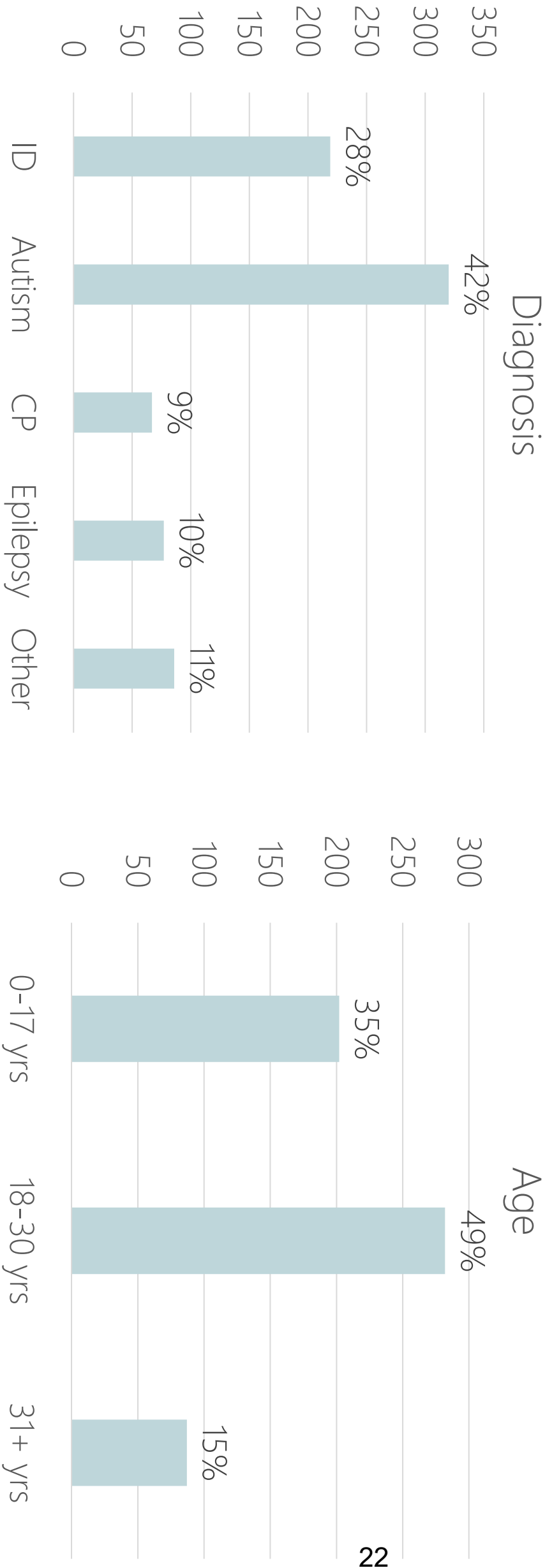
Enrollment Status



Participant Type

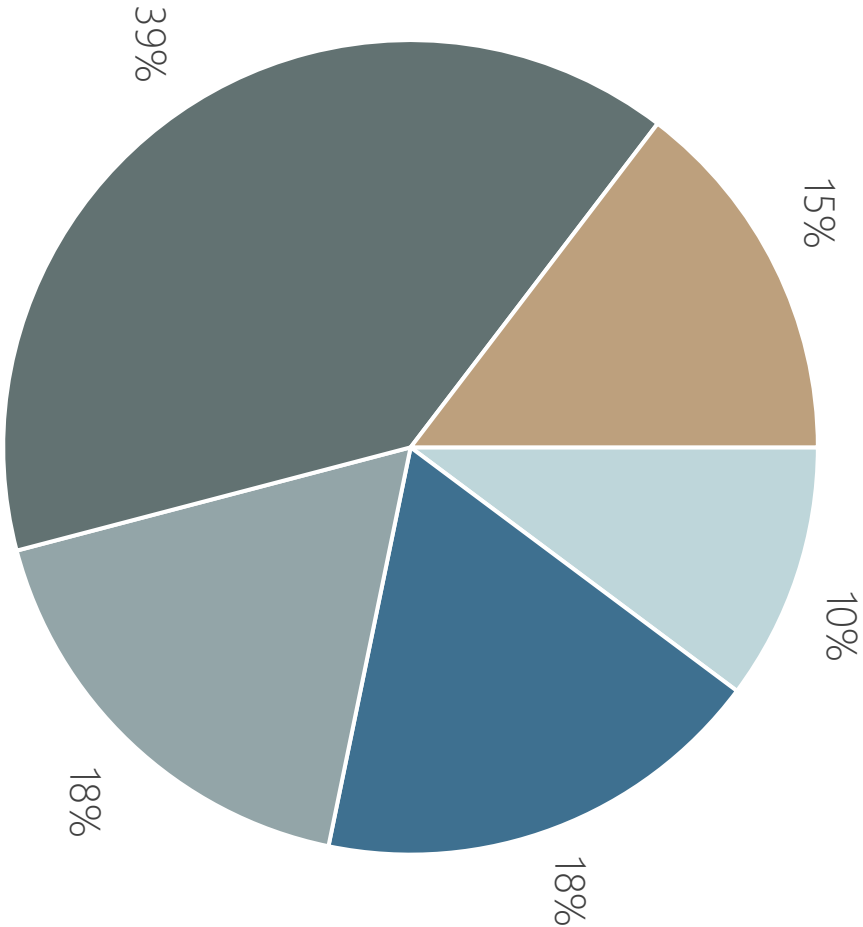


# Participant Diagnosis and Age

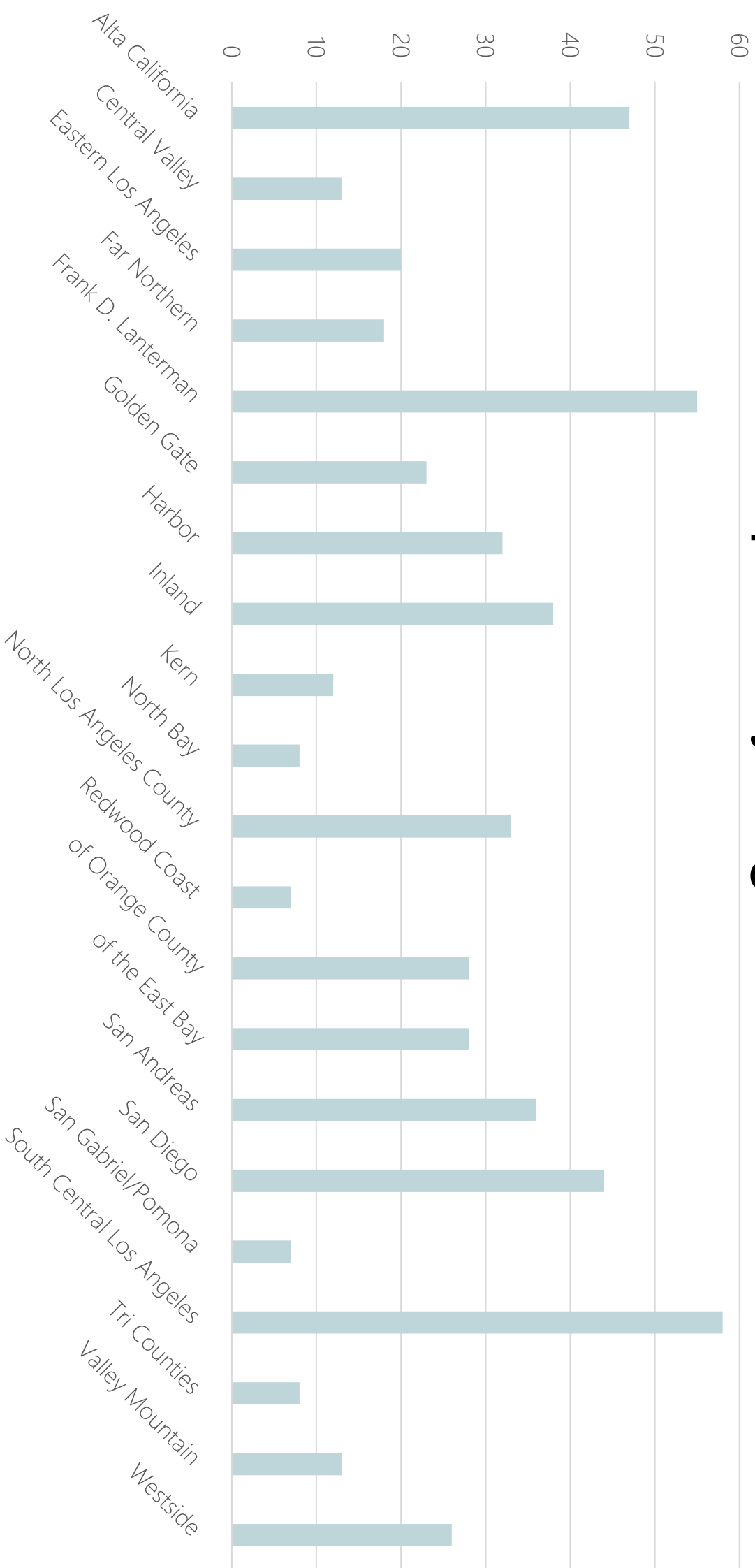


# Participant Race/Ethnicity

Race/Ethnicity



# Participants by Regional Center





# Important Findings: Overall

- **Support for the Concept of SDP (P2, P3)**
  - Many agreed with the idea that people with disabilities and their families should have more freedom to design and pursue their life paths, and with supports of their choosing
  - The concept of the SDP inspired hope, and participants wanted the program to succeed to fulfill its potential
- **SDP Furthers the Principles of Self-Determination (P1, P2, P3)**
  - SDP enhances participants' quality of life
  - SDP furthers freedom, authority, support, responsibility, confirmation in a variety of ways

# Important Findings: Overall

- **Participants Endorse the SDP (P1, P2, P3)**
  - A majority were satisfied and would recommend the program
  - Grateful to be in the Self-Determination Program; find it “life-changing”
  - Believed it was the right choice for them
- **Participants Wish SDP was Easier, with More Support (P2, P3)**
  - Need to reduce the administrative burden, complexity, and demands on participant’s time
  - Call for enhanced supports for participants and families through information availability, staff training, and capacity

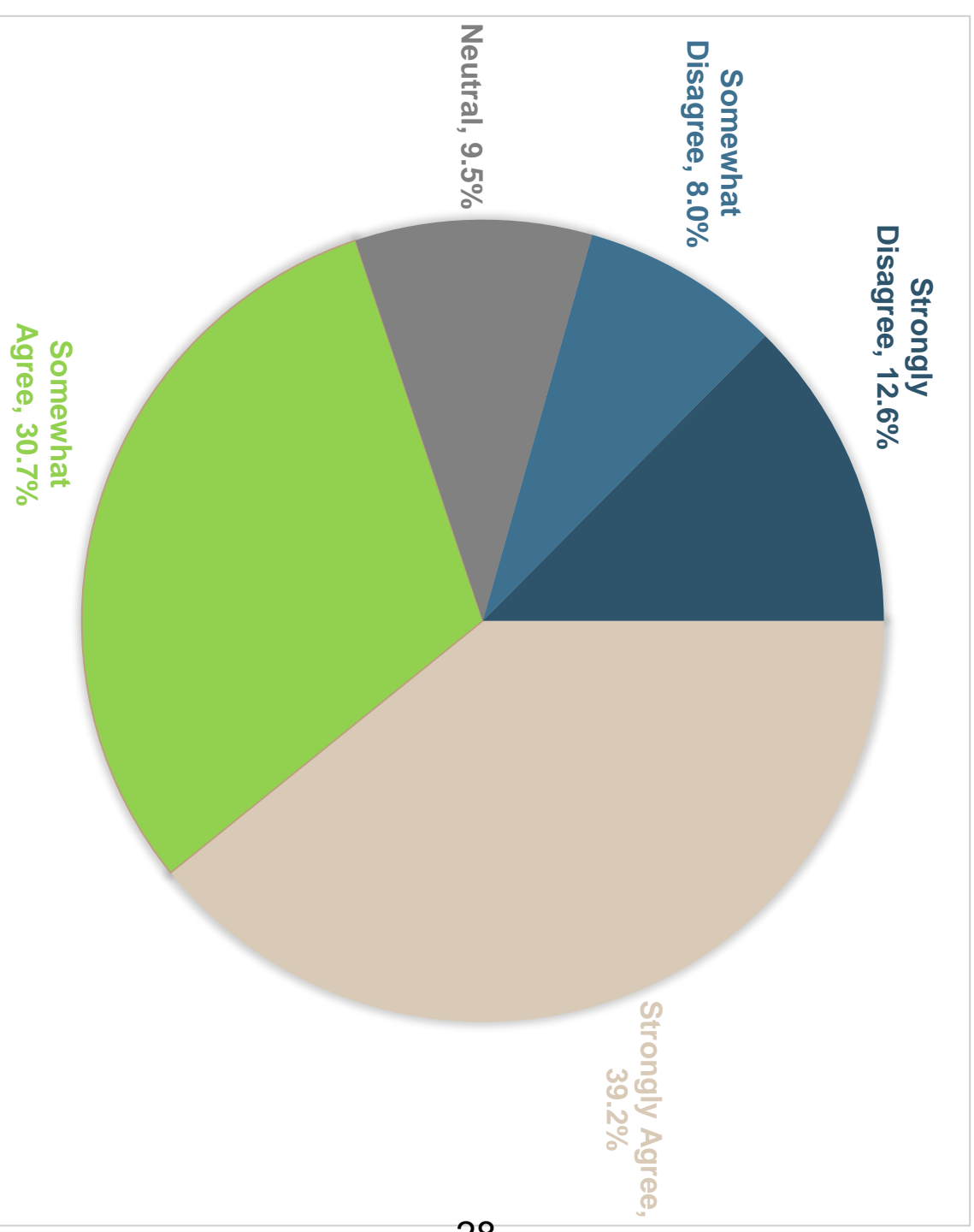
# Important Findings: Overall

- **Inequities Exist in the SDP** (P1, P2, P3)
  - Participants described inequities on the basis of race, Regional Center, disability, socioeconomic/education, native language, and urbanicity (P2, P3)
  - Less Support, Lower Satisfaction, yet Higher Positive Outcomes for BIPOC Participants (P1, P3)
  - SDP is Harder to Navigate for Younger Participants (P1, P3)
  - SDP is Harder to Navigate for Autistic Participants (P1, P3)

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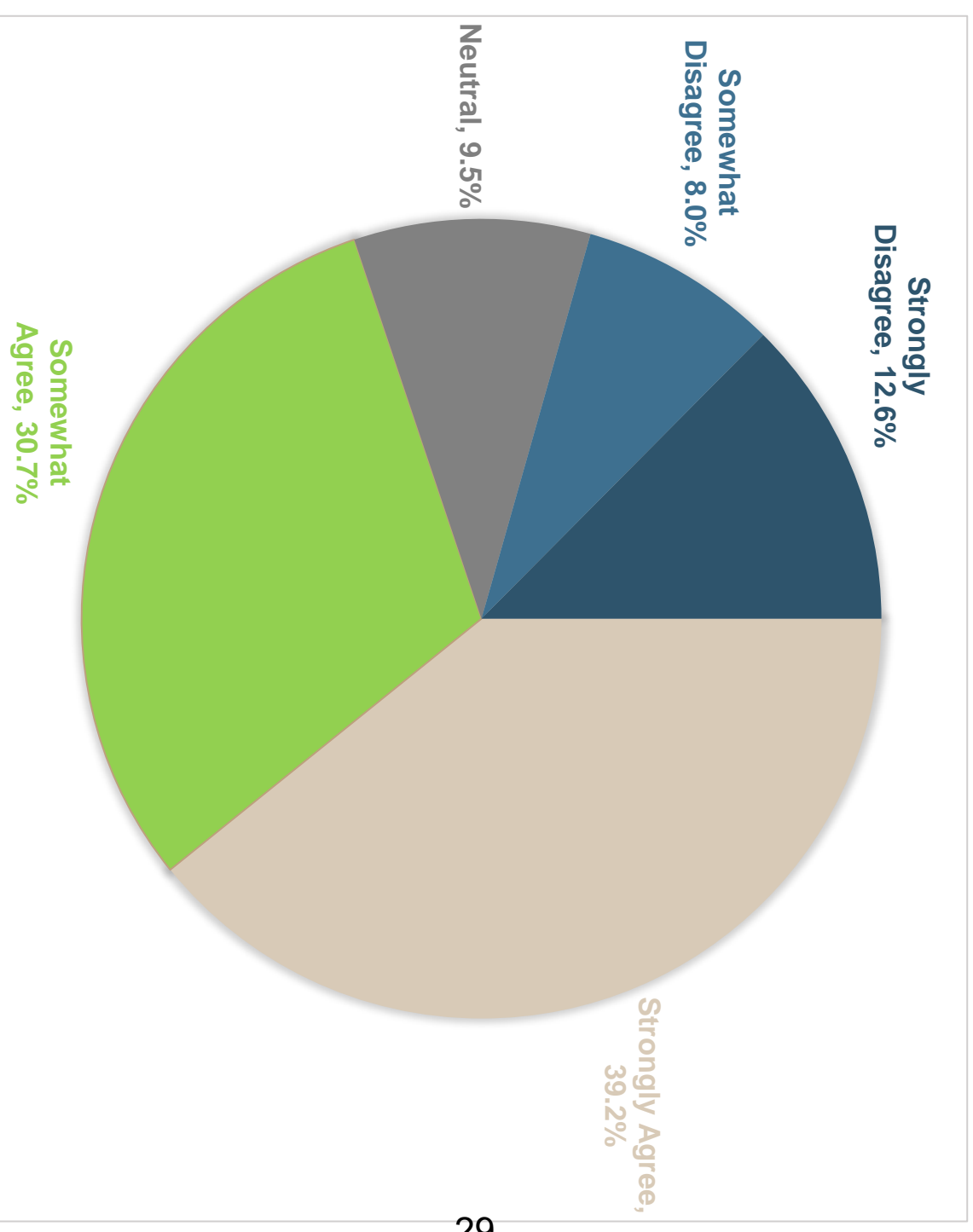
**Most SDP participants expressed some level of positive agreement with the statement:**

*I am pleased with my overall experience in Self-Determination Program.*



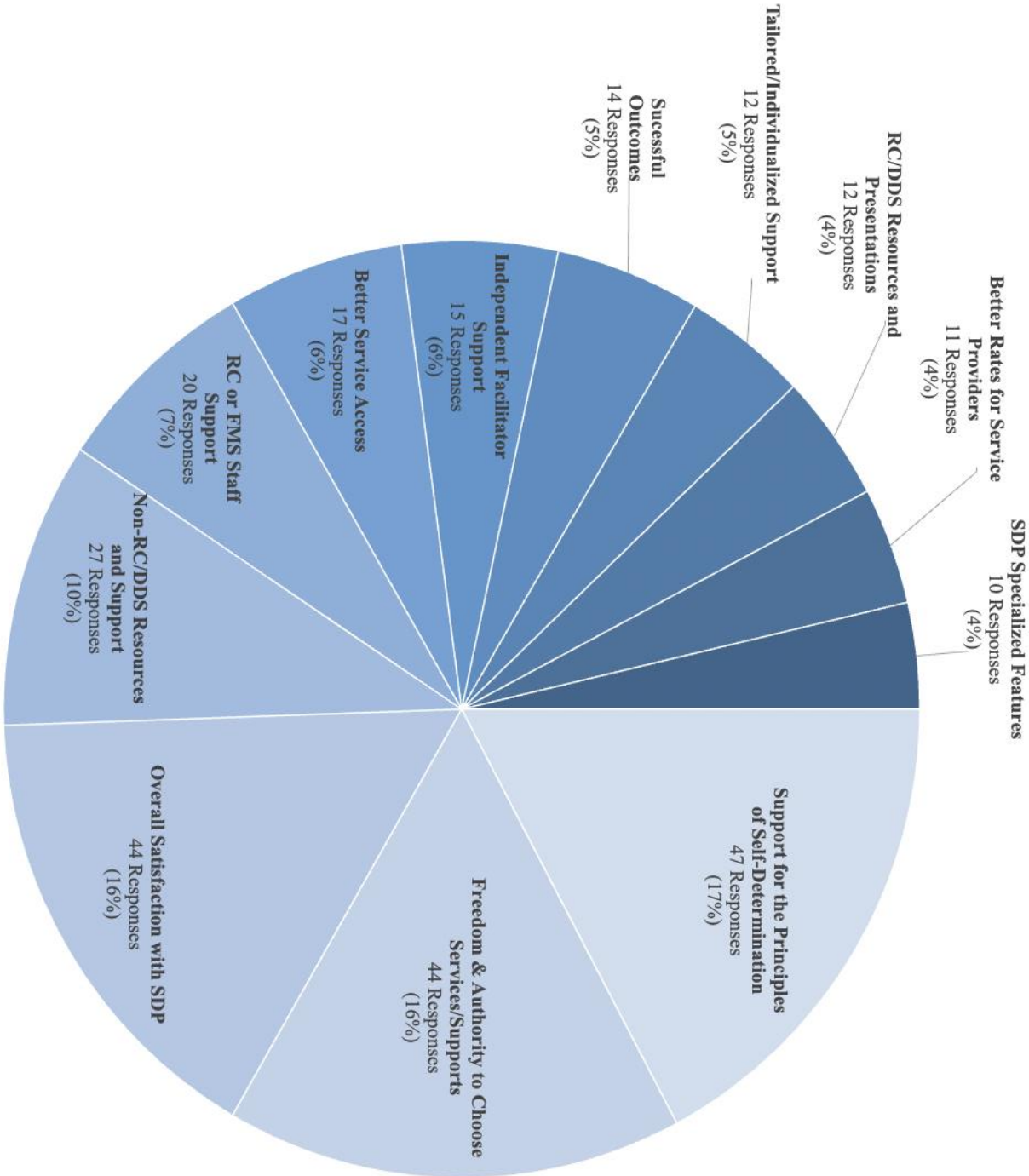
Most SDP participants would **recommend the Self-Determination Program** through endorsement of the statement:

*I would recommend the Self-Determination Program.*



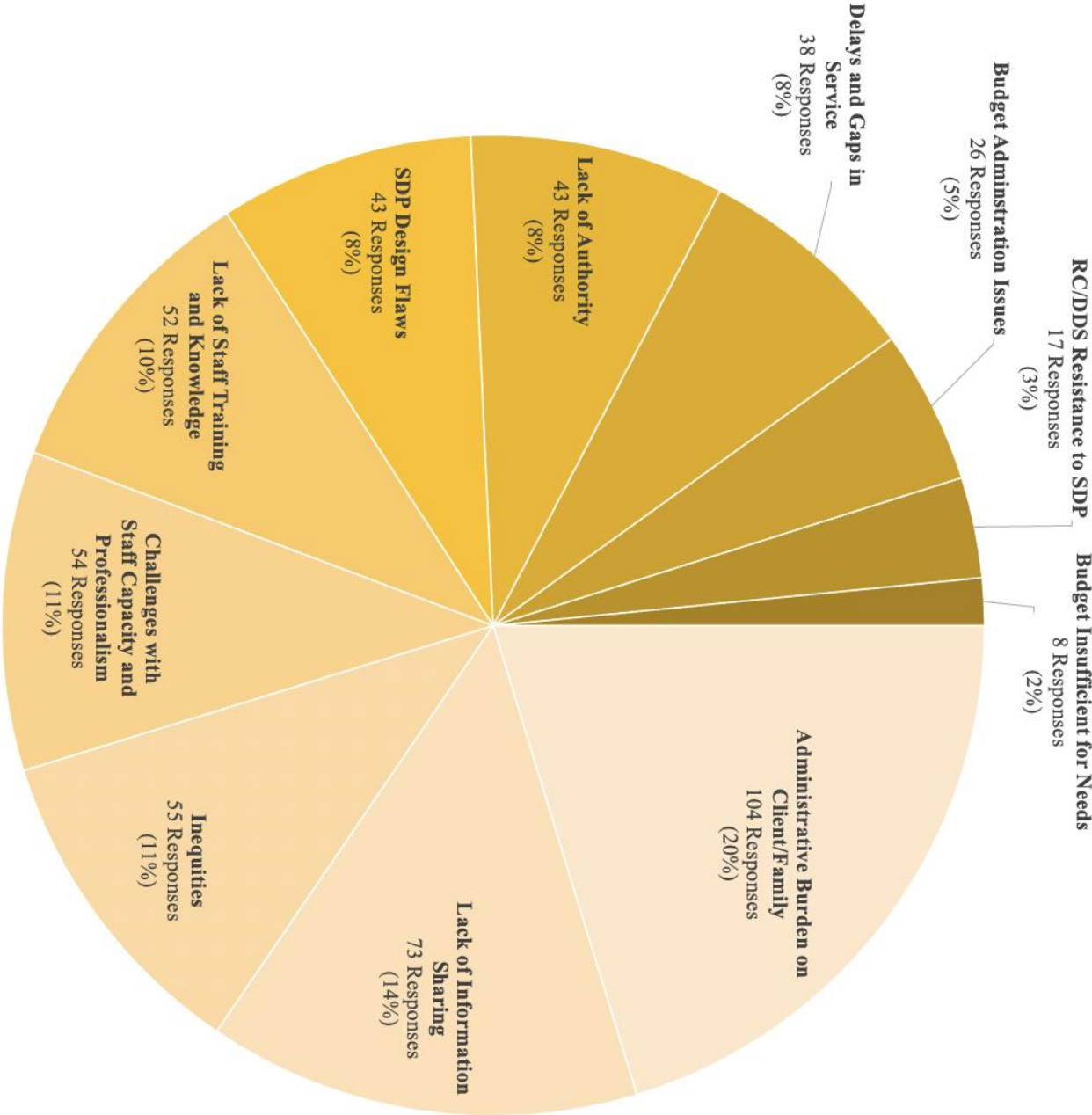
# Important Findings:

## What people like about SDP



# Important Findings:

## Current Barriers and Challenges



# Recommendations

- Improve Access to Information about SDP
- Streamline the Enrollment Process
- Streamline the Budgeting Process
- Reduce Administrative Burden
- Improve Compensation and Capacity of Independent Facilitators
- Leverage SDP as a Model to Improve Workforce Hiring and Retention
- Create a More Equitable System to Mitigate Disparities

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# Thank you!

## Questions and discussion

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**JULY 17, 2023**  
**AGENDA ITEM 9**  
**INFORMATION ITEM**

**SELF ADVOCATES ADVISORY COMMITTEE**  
**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

***Reflections on the Americans with Disabilities Act (ADA) and Next Steps***

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July 26<sup>th</sup>, 2023 will mark the 33<sup>rd</sup> Anniversary of the Americans with Disabilities Act (ADA). The ADA is a groundbreaking civil rights law that was signed into law by President George H.W. Bush on July 26, 1990. The ADA prohibits discrimination against people with disabilities in all areas of public life: in the workplace, at school, public transportation and public and private places that are open to the general public. Since the enactment of the ADA, California and the USA have seen both legislative and social change regarding accessibility, but there is still room for improvement.

This agenda item is an opportunity to have a conversation about the successes and the challenges you have experienced or heard about since the passage of the ADA. In preparation for this discussion, SAAC members are encouraged to think about the following questions:

- What words do you think of when you hear ADA?
- How have you or someone you know been impacted by the passage of the ADA?
- Why is it important to reflect on legislative “wins” like the passage of the ADA?
- Do you have any recommendations on what the State Council on Developmental Disabilities (SCDD) should be working to address access barriers?

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**JULY 17, 2023**  
**AGENDA ITEM 10**  
**INFORMATION ITEM**

**SELF ADVOCATES ADVISORY COMMITTEE**  
**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES**

***Adjournment***

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The next committee meeting is scheduled for September 18, 2023.

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