

# ***It Holds So Much Promise:***

## **An Evaluation of Participant Experiences in California's Self-Determination Program**

UCLA Tarjan Center  
Distinguished Lecture Series  
5.19.2025

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# Welcome & Overview

- Brief History of the Self-Determination Program
  - Pilot began in 1998 – 5 regional centers
  - SB 468 signed in 2013 – phase-in
  - July 2021 – anyone eligible
- What is the Self-Determination Program?
  - Alternative way to access regional center services

# Welcome & Overview

- 5 Principles of the Self-Determination Program
  - Freedom
  - Authority
  - Support
  - Responsibility
  - Confirmation

# Welcome & Overview

- Why This Report?
  - Required by CA Statute
  - Assess how SDP aligned with 5 Principles
  - Due to Legislature June 2023
- Who Led the Report?
  - SCDD, UCLA Tarjan Center, DRC

# Lived Experience



# Main Points to Remember

- We hope you will walk away from today's session with:
  - How we got the information from our community
  - What we found
  - How the data is driving change

# Community Engagement in Program Evaluation

Christine Moody, UCLA Tarjan Center



# Outreach Plan

- Survey and Focus Groups
- Diverse voices
- Incentives to participate
- Mailed to Regional Center clients
- Distributed through federal partners' networks



# Focus Group Accessibility

- Offered on Zoom in the evening
- Live Spanish translation
- Questions designed to be non-leading and balanced
- All materials reviewed by people with developmental disabilities

# Focus Group Interest

- 9 focus groups
  - Enrolled participants
  - Not enrolled regional center clients
  - Family members of enrolled participants
  - Family members of not enrolled regional centers clients
  - Independent facilitators
- Enthusiastic response – over 1500 people signed up
- Created “qualitative survey” to hear more voices
- Survey translated into 10+ languages

# Focus Group Participant Selection

- Invited participants to mirror California Department of Developmental Services demographics
  - Race
  - Age
  - Diagnosis
  - Gender
  - Language
  - County

# Program Evaluation Phases

$N = 604$

## Phase 1 (P1)

### Quantitative Survey

- Distributed late 2022
- 242 respondents

## Phase 2 (P2)

### Virtual Focus Groups

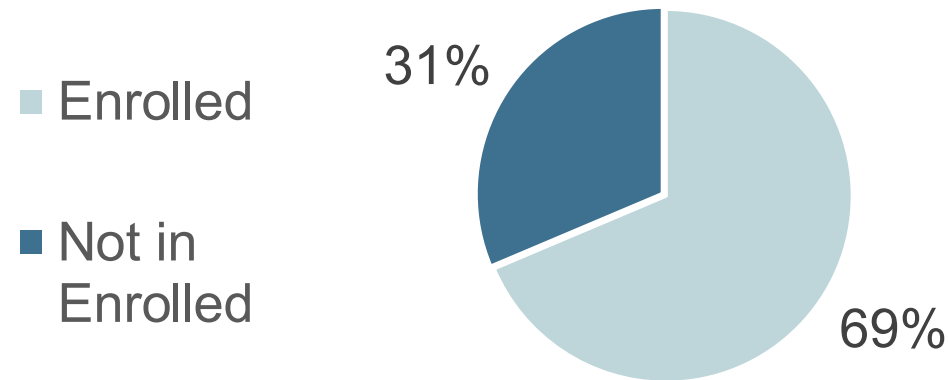
- April 2023
- 97 participants

## Phase 3 (P3)

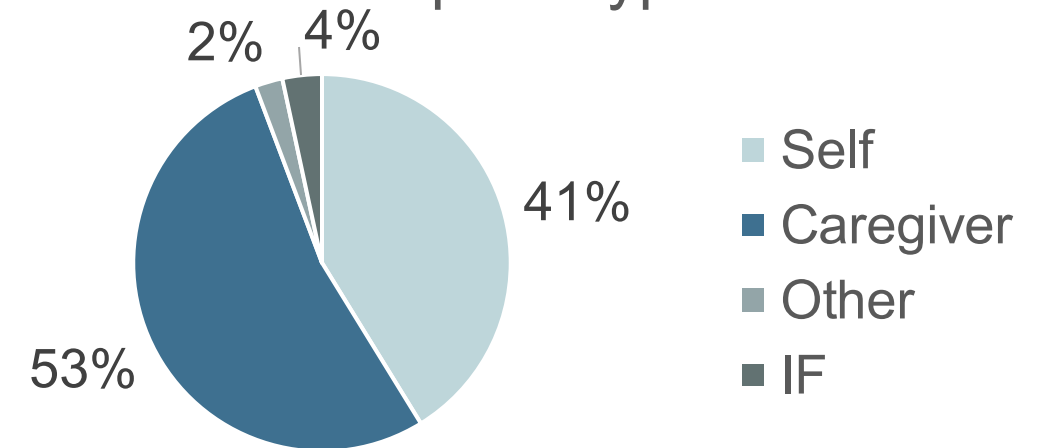
### Qualitative Survey

- May 2023
- 265 respondents

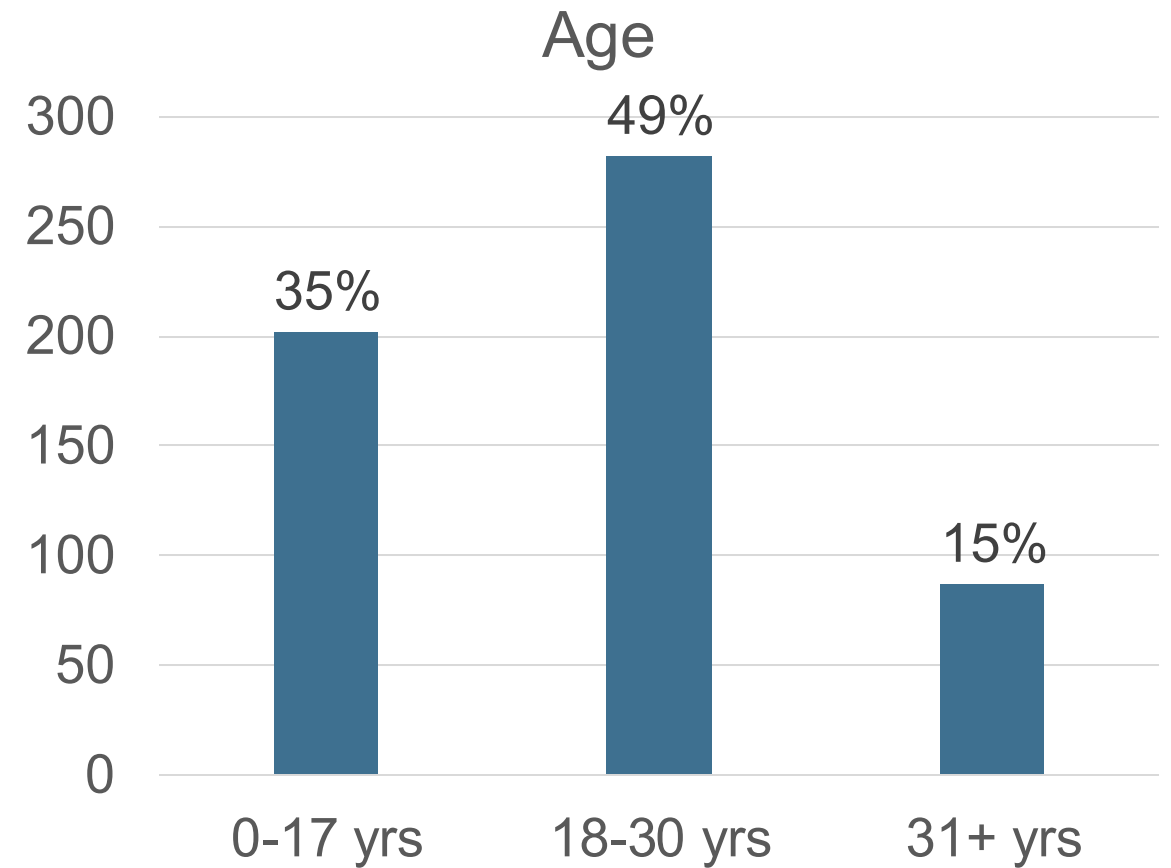
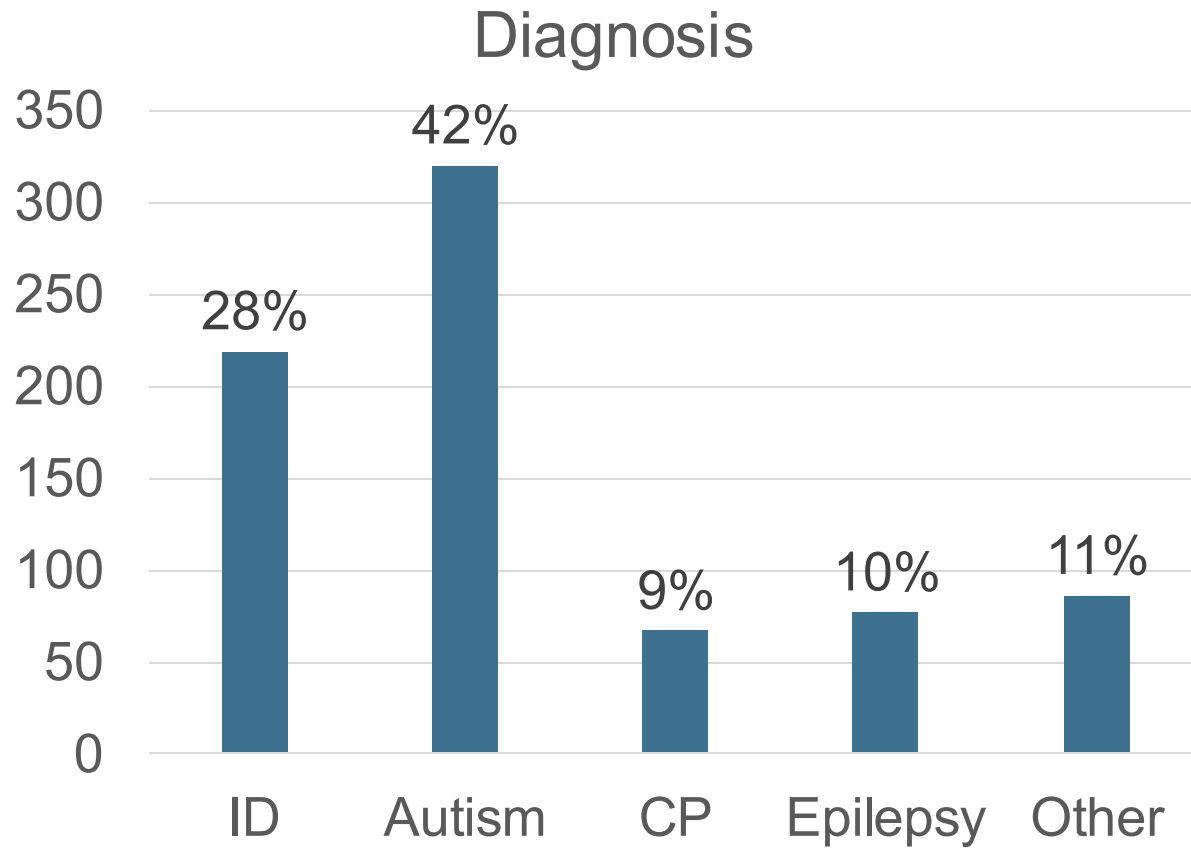
Enrollment Status



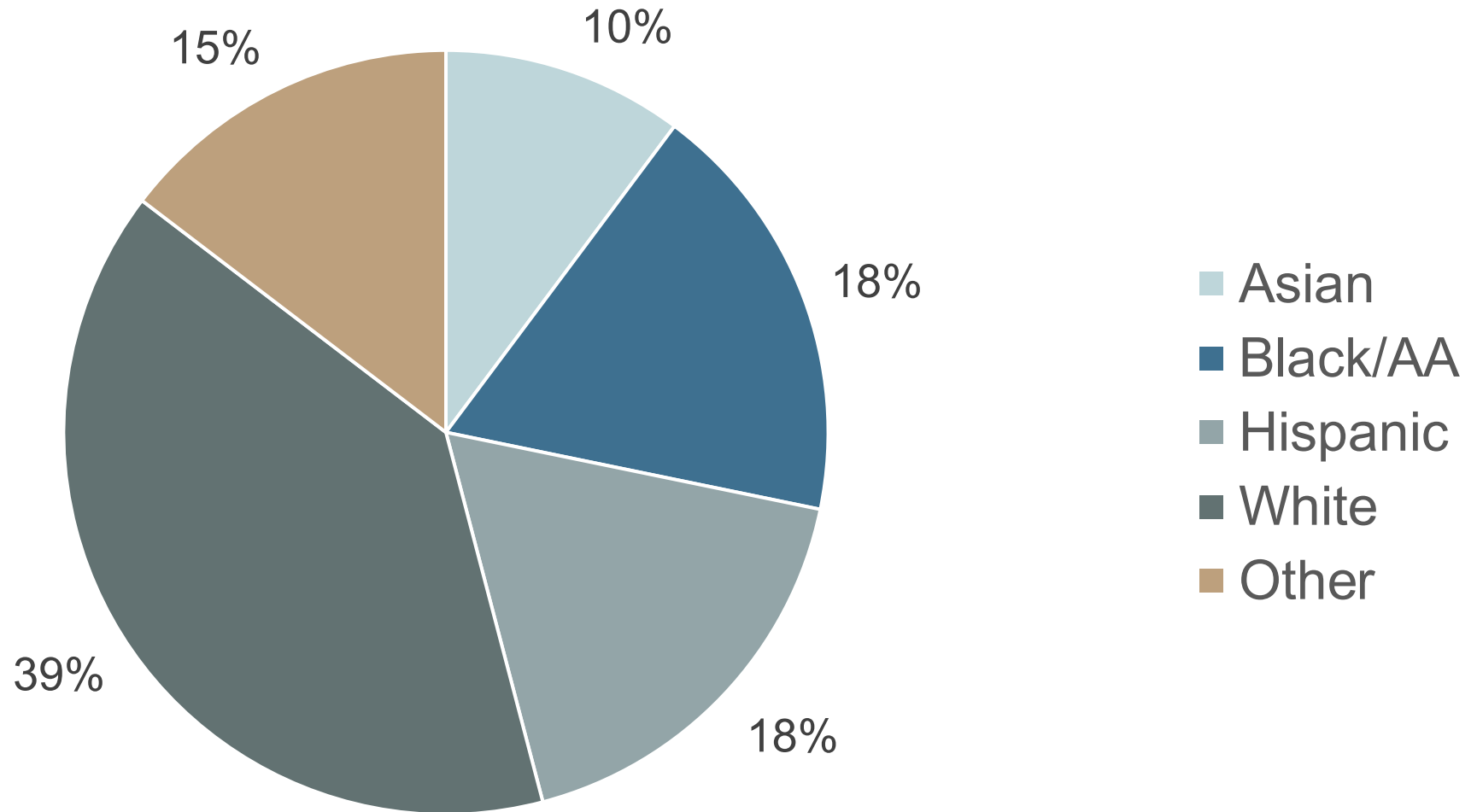
Participant Type



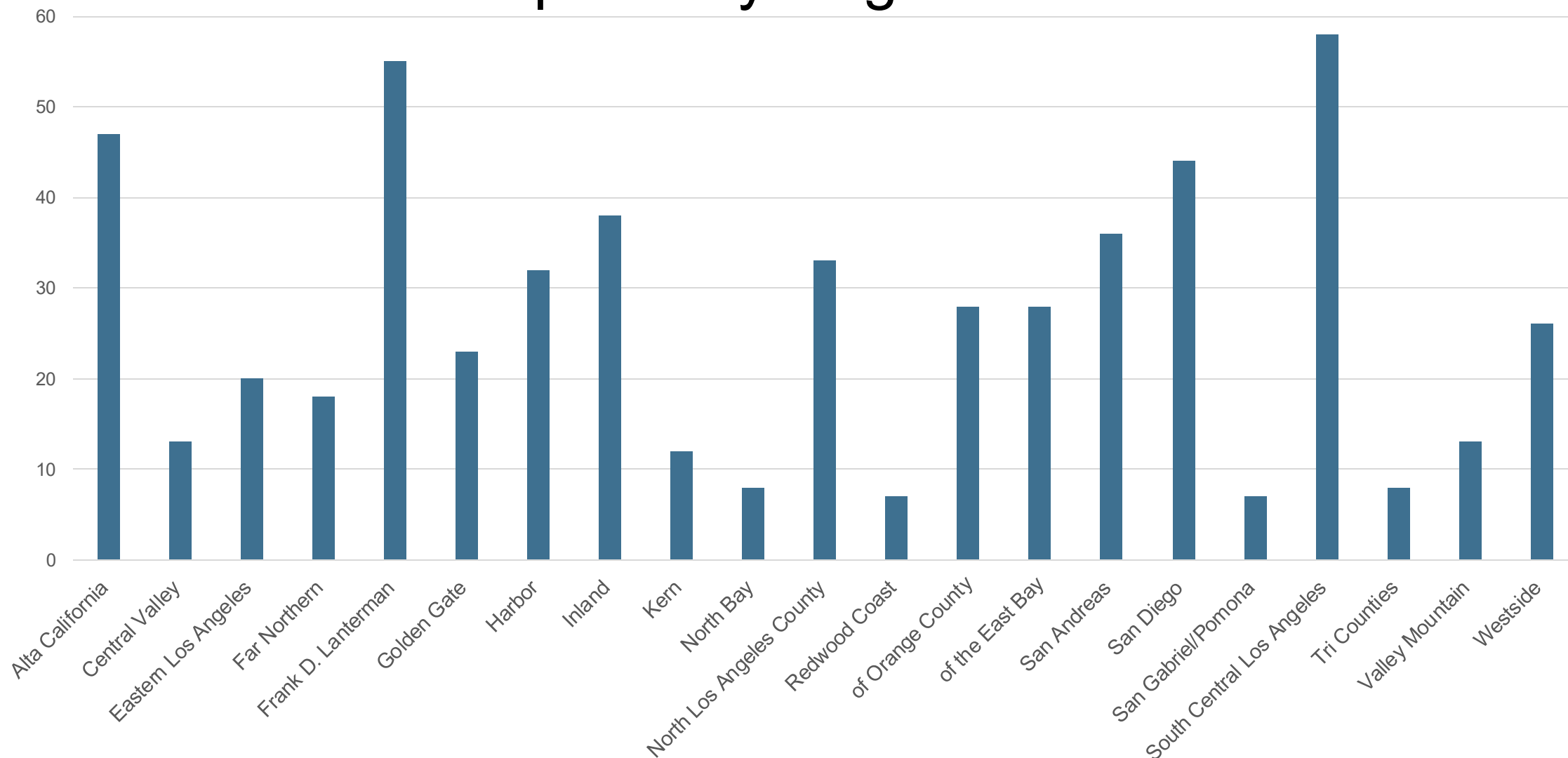
# Participant Diagnosis and Age



# Participant Race/Ethnicity



# Participants by Regional Center





# What We Learned about California's Self-Determination Program

Christine Moody, UCLA Tarjan Center

# Important Findings: Overall

- **Support for the Concept of SDP (P2, P3)**
  - Many agreed with the idea that people with disabilities should have more freedom to design and pursue their life paths, with supports of their choosing
  - The concept inspired hope, and people want the program to succeed
- **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

*“With Self-Determination I have more freedom to choose who helps me get things done. My staff is now someone I trust and not a stranger... I love that I have a spending plan that I can see and understand.”*

– Current SDP Participant

*“SDP has been life-altering... My son makes all of the decisions in his life now. He receives social support in a natural environment doing the things he loves. He has support taking a college course at the local junior college. He is working with supported employment and has had a paid internship at his favorite comic bookstore. He travels independently to hang out with friends.*

– Family member of a Current SDP Participant

*“My services [in SDP] better meet my needs than the vendors through the traditional model... SDP has improved my quality of life. I’m receiving the in home and community support I need.”*

– Current SDP Participant

# Important Findings: Overall

- **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

*“I really wish it was more of a one stop shop where you could get your services started and finalized in one agency. Having so many agencies and choices and decisions to make is confusing to myself and has made it difficult moving forward. I think removing a lot of the complications involved with self-determination would be helpful. I've been trying for over 2 years to finalize my enrollment.”*

– Regional Center Client Interested in SDP



*“Parents are already overwhelmed... It is a lot to deal with all the steps to get the services and to chase down paperwork, spending plans, signatures and people... Simplify this process even more, somehow, some way.”*

- Family member of a Current SDP Participant

# Important Findings: Overall

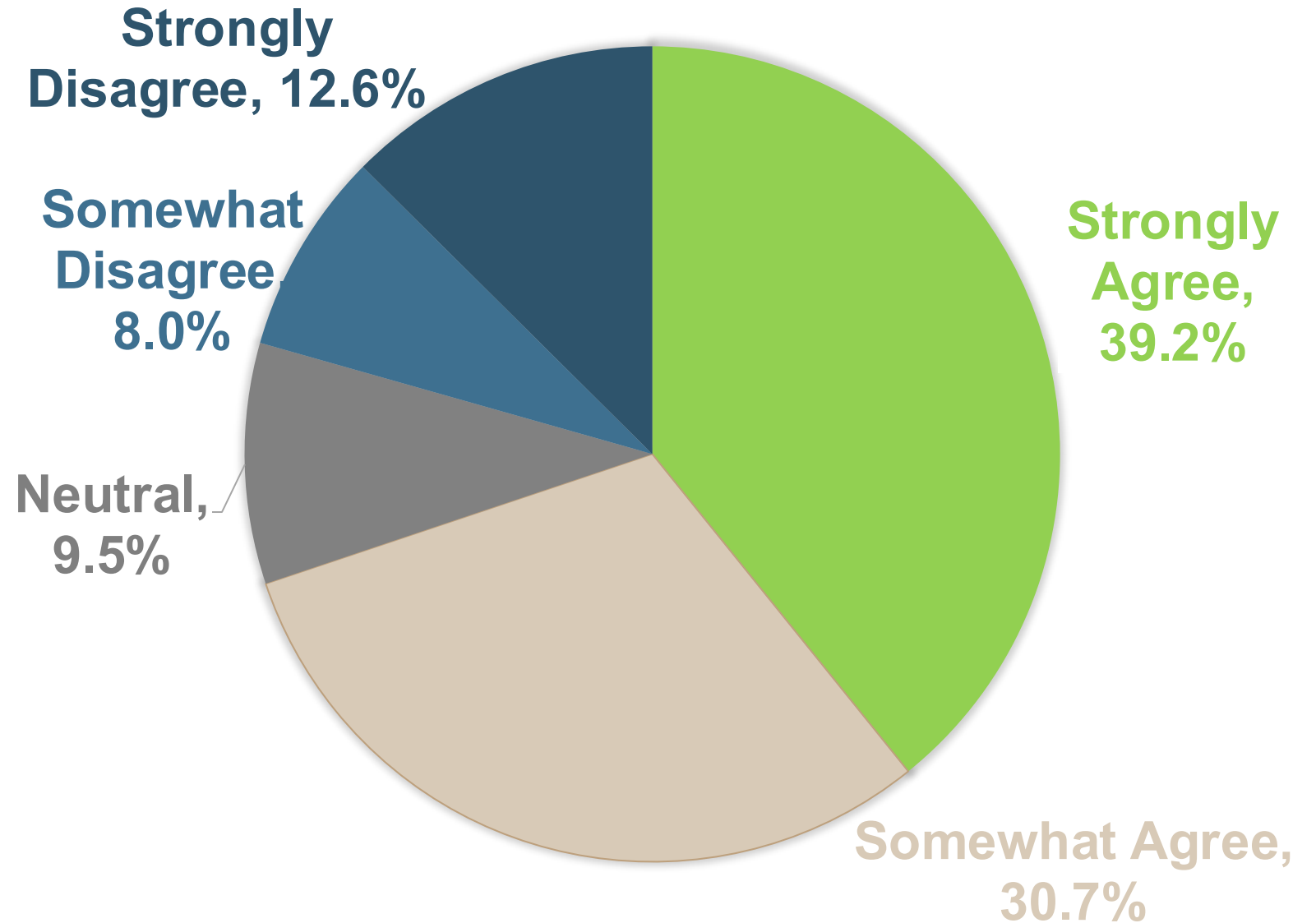
- **Inequities Exist in the SDP (P1, P2, P3)**
  - Participants described inequities on the basis of race, Regional Center, disability, socioeconomic/education, native language, and urban/city (P2, P3)
  - Less Support, Lower Satisfaction, yet Higher Positive Outcomes for BIPOC Participants (P1, P3)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

*“[I am a] highly educated professional with an MA, able to reduce my work hours so I can keep this SDP going, and I am having a very hard time... How is this ever going to be accessible for non-native English speakers, [those] who can't afford to work less, [those] who may not have much support?”*

- Family member of a Current SDP Participant

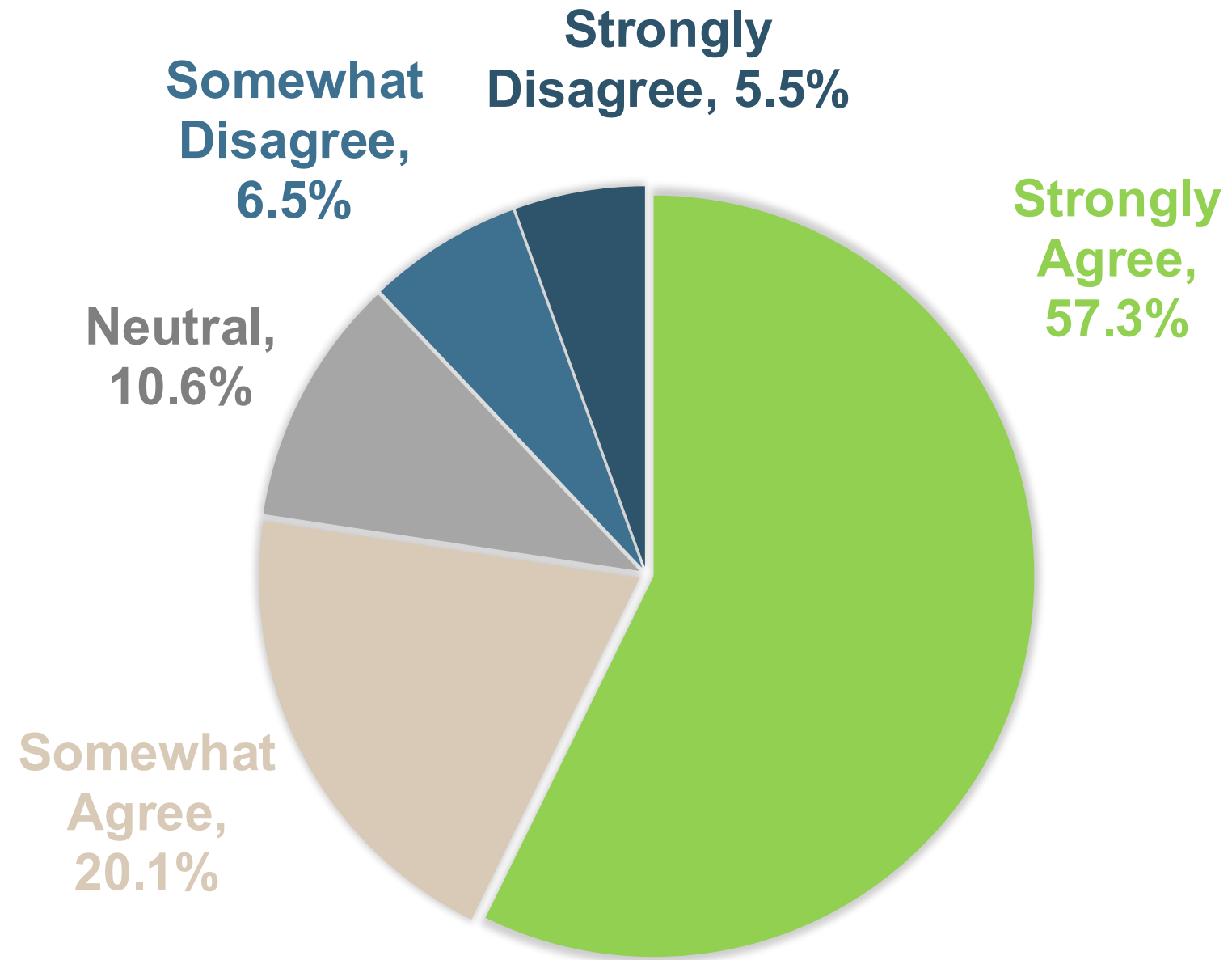
Most SDP participants expressed some level of **positive** agreement with the statement:

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



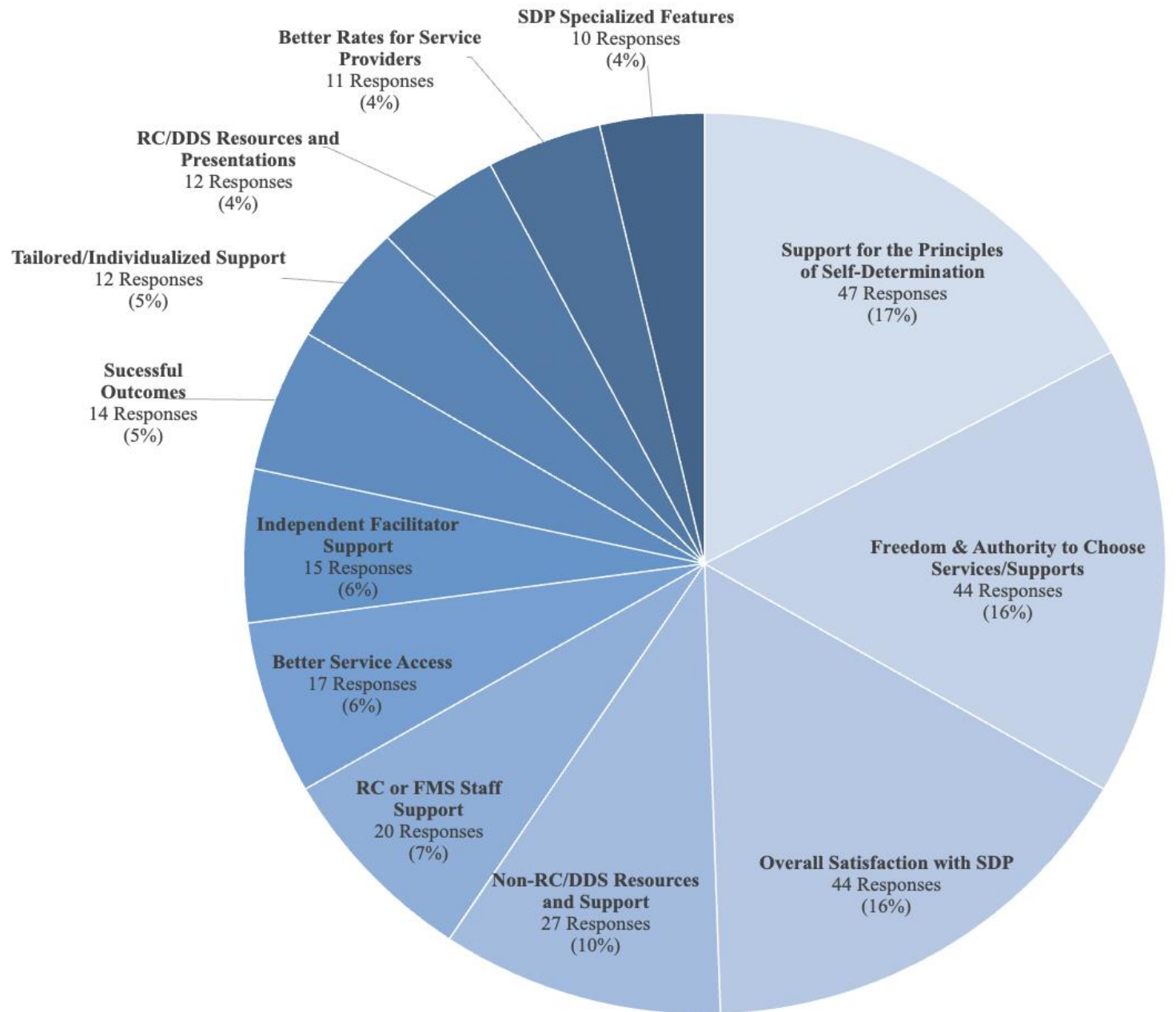
Most SDP participants would **recommend** the Self-Determination Program through endorsement of the statement:

*I would recommend the Self-Determination Program.*



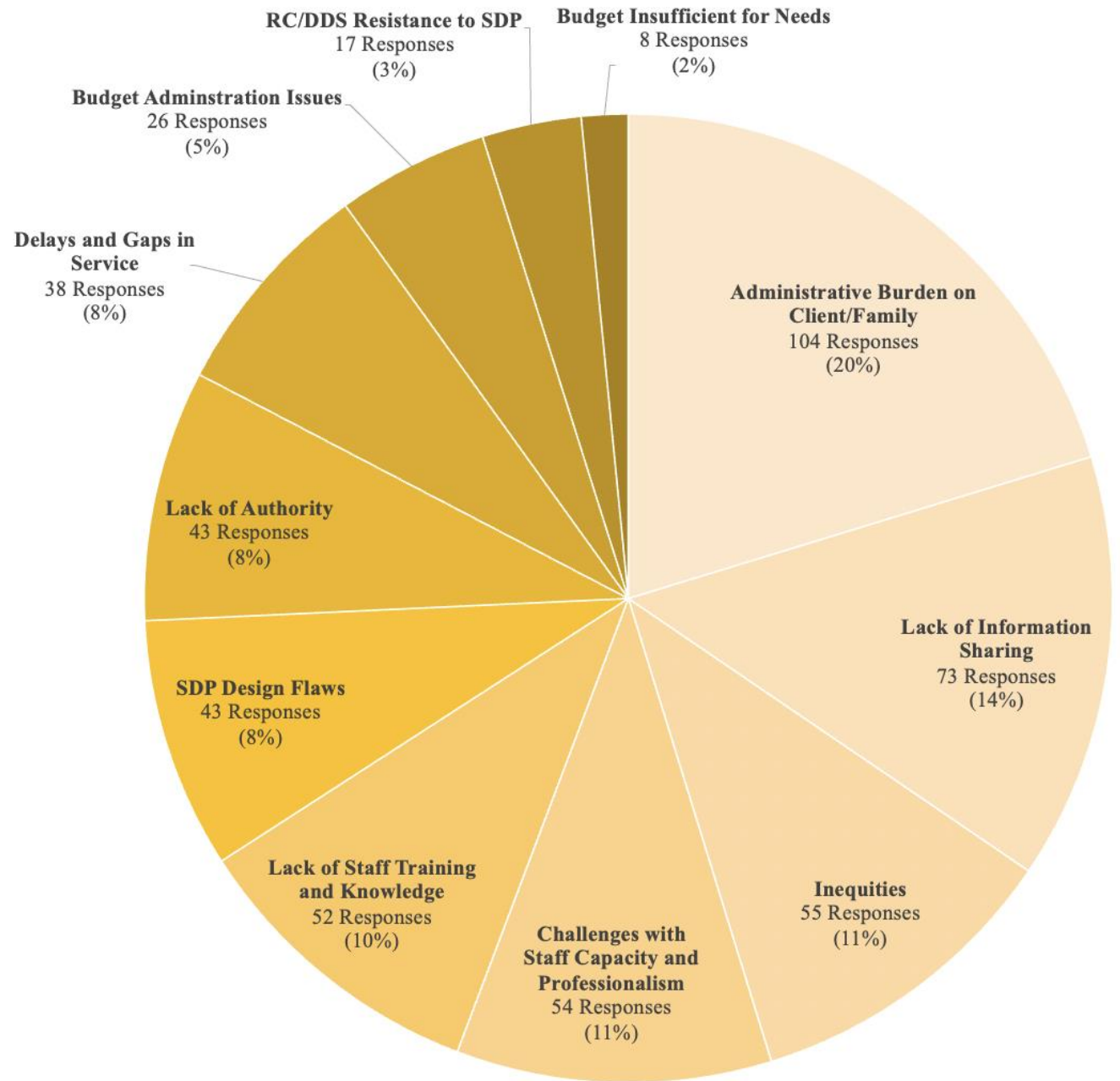
# Important Findings:

## What people like about SDP



# Important Findings:

## Current Barriers and Challenges



*“It holds so much promise! ... I believe [SDP is] the best path forward for the IDD community, but we have many potholes to fill and a lot of bumps still to navigate.”*

– Family member of a Current SDP Participant



# Using Program Evaluation Data to Make Progress

Christine Tolbert, SCDD SDP Manager

# Key Audiences for the Report

- California State Legislature
- Department of Developmental Services (DDS)
- Federal Partners
  - SCDD, UCLA Tarjan Center, and Disability Rights CA
- Regional and State Consortia, Advocacy Organizations

# Public Availability of Report

- Available on the SCDD website
  - Full Report
  - Executive Summary
  - Plain Language Executive Summary
    - Translations in multiple languages
- Media Coverage:
  - Los Angeles Times Article
    - Highlights some findings
    - SDP & underserved communities

# 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

# New Directives Following the Report

- DDS has issued **25 new directives for the SDP** since July 1, 2023
- Many are related to report recommendations:
  - Financial Management Services (FMS)
  - Billing requirements
  - Reporting requirements on SDP from regional centers
  - Expanded clarification on goods and services
  - Clarification on payments for trained supports to get enrolled

# Proposed Legislative Action SB 1281 (Menjivar)

- SB 1281 introduced 2/15/24
  - Senator Caroline Menjivar (D – San Fernando Valley)
- Purpose: Equity and Access in SDP
  - Streamlining processes
  - Support choice for services
  - Improve transition support
  - Improve Financial Management Services (FMS)
- Outcome: Bill vetoed by Governor
  - DDS Master Plan

# Master Plan for Developmental Services – SDP Points

- Improve Access to Information & Clarify Roles
- Streamline Enrollment
- Reduce Administrative Burden / Simplify Spending Plans
- FMS Enhancements (accountability, labor laws, timely payments)
- Promote Equity & Inclusion - Diversity of Participants
- Enhance Orientations
- Ensure Person-Centeredness - All Services

# Moving Forward

- Continued Advocacy
  - Make it easier for participants and families to understand and access
  - Streamlining processes across the state
- Data Needs
  - Comparison of outcomes in SDP vs. Traditional Services
  - Differences in barriers by demographic group, including differences for BIPOC, younger, and Autistic participants
- Future considerations
  - Gather perspectives from regional center service coordinators





# THANK YOU!

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For full program evaluation report  
and executive summaries in Plain  
language, Spanish, Chinese,  
Vietnamese, please visit:

# Question & Answer

