2027 – 2031 STATE PLAN DEVELOPMENT

STATEWIDE SURVEY
DATA ANALYSIS
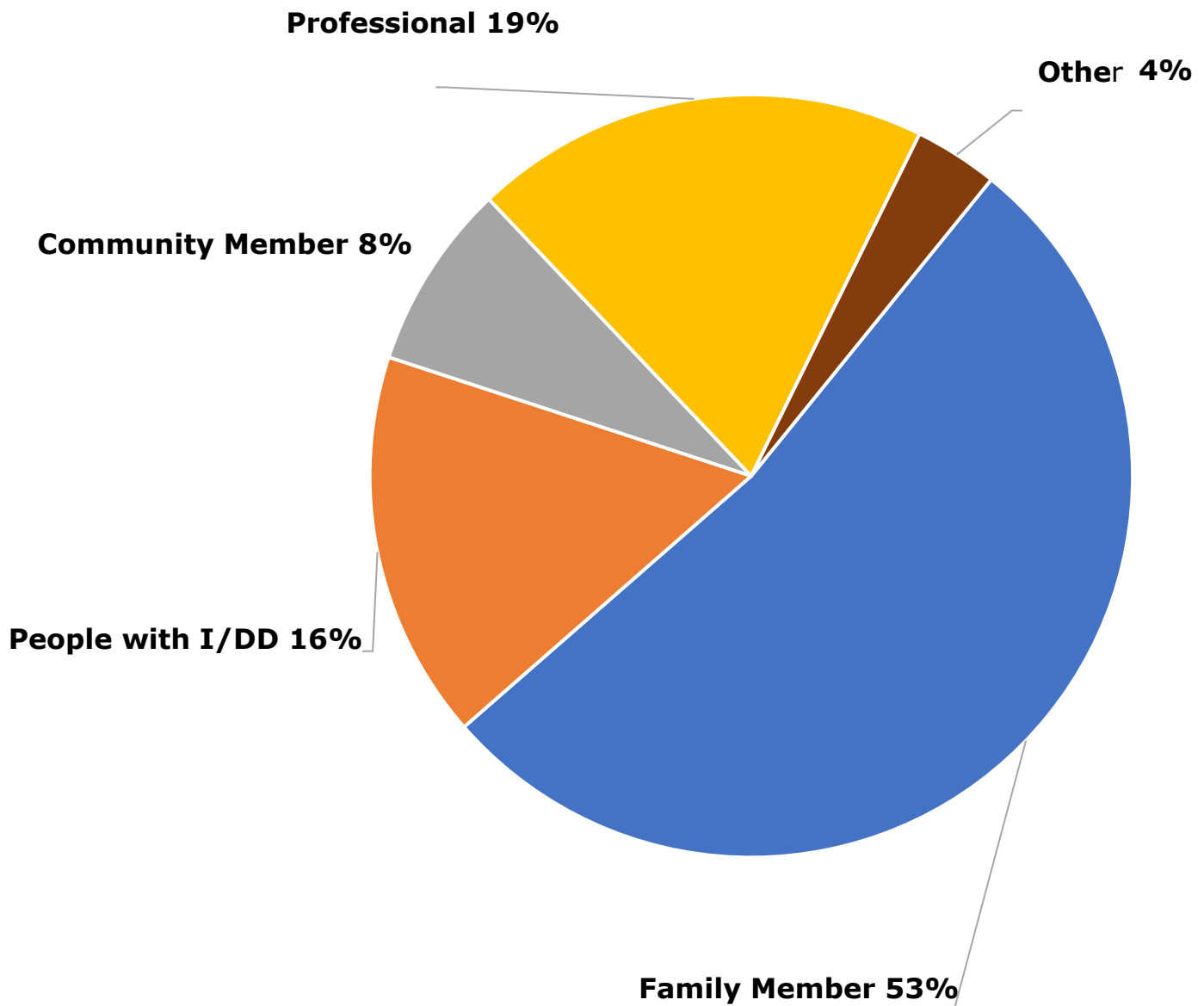
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RESPONDENT OVERVIEW

Total Number of Responses: 4,197

Respondent Groups

Professional 19%

Other 4%

Community Member 8%

People with I/DD 16%

Family Member 53%

Geographic Distribution

Region	Value
North Coast	94
North State	101
Sacramento	227
North Bay	165
Bay Area	256
North Valley Hills	131
Central Coast	249
Sequoia	77
Los Angeles	382
Orange County	687
San Bernardino	479
San Diego Imperial	170
I do not live in CA	11
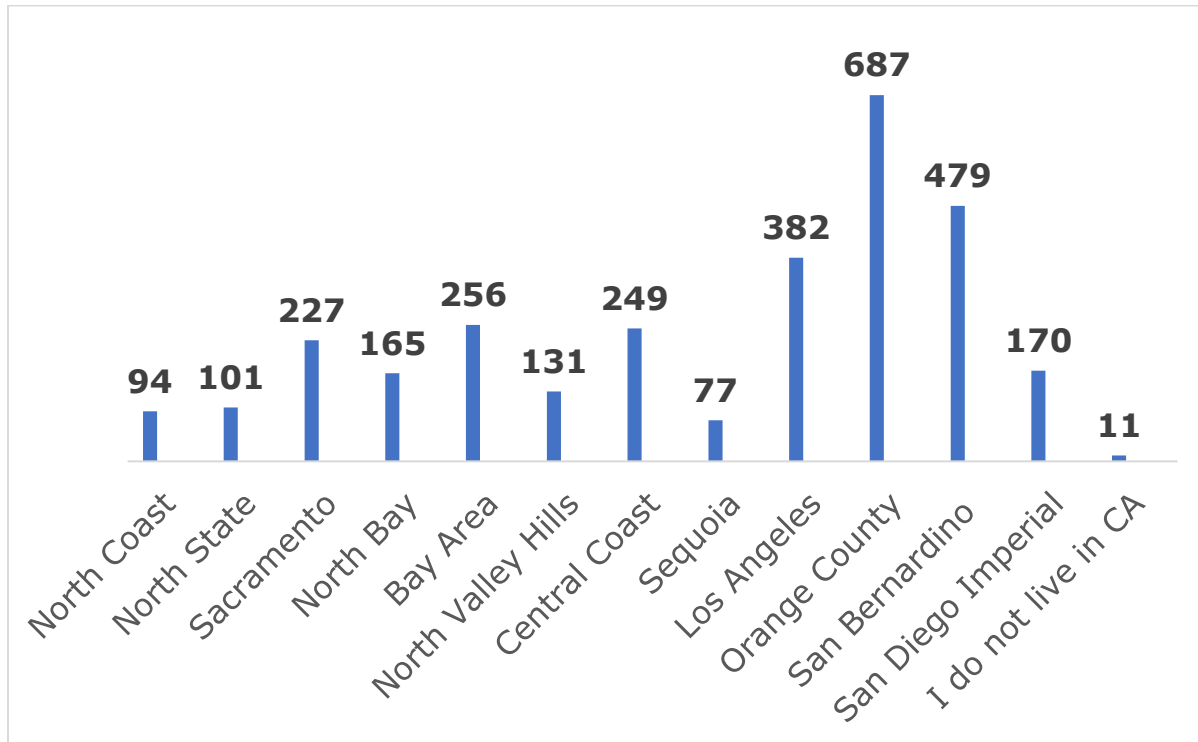
Languages

Language	Total	People with I/DD	Family Members
English	3,655	791	2,152
Spanish	382	31	340
Chinese	99	1	93
Korean	33	1	29
Japanese	27	1	26
French	1	-	1

GOAL 1

SELF-ADVOCACY

SELF-ADVOCACY

Top Selected Challenges (all Respondents)

Challenge	Count
Regional Centers	1,677
Housing	1,429
Employment	1,299
Social inclusion	1,228
Health	1,210
Independent/supported living services	1,133
Future Planning	1,072
Public awareness gaps	975
Education	831
Safety	745
Civil rights	724
Transportation	717
Discrimination	640
Recreation	585
Abuse and/or neglect	437
Access to assistive technology	425
Early identification and intervention	396
Childcare	310
Accessibility of public spaces	300
Other	255

Top Selected Challenges (by Group)

	People with I/DD	Family Members	Others
1	Housing	Regional Centers	Regional Centers
2	Regional Centers	Housing	Housing
3	Employment	Social inclusion and community engagement	Employment
4	Civil Rights	Independent and supported living services	Health access
5	Formal and informal community support	Health access	Social inclusion and community engagement
6	Transportation	Employment	Transition to adulthood/ future planning
7	Community Inclusion	Transition to adulthood and future planning	Public awareness gaps
8	Safety	Public awareness gaps	Independent and supporting living services
9	Transition to adulthood/future planning	Education	Transportation
10	Self-Determination	Recreation	Civil Rights

Question:	What types of activities would help self-advocates or people with intellectual and/or developmental disabilities the most?

Top Selected Self-Advocacy Activities (all Respondents)

Activity	Count
Community-building	2,065
Support groups/mentoring opportunities	1,934
Resources (tip sheets, toolkits, printed materials etc.)	1,632
Events	1,590
Self-advocacy groups	1,476
Peer leader/trainer development	1,271
Technical assistance (TA) clinics	1,211
Staff-led training	1,264
Peer-led training	1,131
Leadership opportunities	977
Chats	826
Public-speaking opportunities	761
Other	367
Personal or group staff support to answer your questions	12

Top Requested Self-Advocacy Activities (by Group)

	People with IDD	**Family Members**	**Others**
1	**Self-advocacy groups**	**Community-Building**	**Community-Building**
2	**Support groups/mentoring opportunities**	**Support groups/mentoring opportunities**	**Support groups/mentoring opportunities**
3	**Community-Building**	**Resources**	**Resources**
4	**Public-speaking opportunities**	**Events**	**Self-advocacy groups**
5	**Leadership Opportunities**	**Self-advocacy groups**	**Events**
6	**Peer leader/trainer development**	**Technical Assistance (TA) Clinics**	**Peer leader/trainer development**
7	**Events**	**Staff-led training**	**Technical assistance clinic**
8	**Resources**	**Peer leader/trainer developmen**	**Peer-led training**
9	**Chats**	**Peer-led training**	**Leadership Opportunities**
10	**Peer-led training**	**Leadership opportunities**	**Staff-led training**

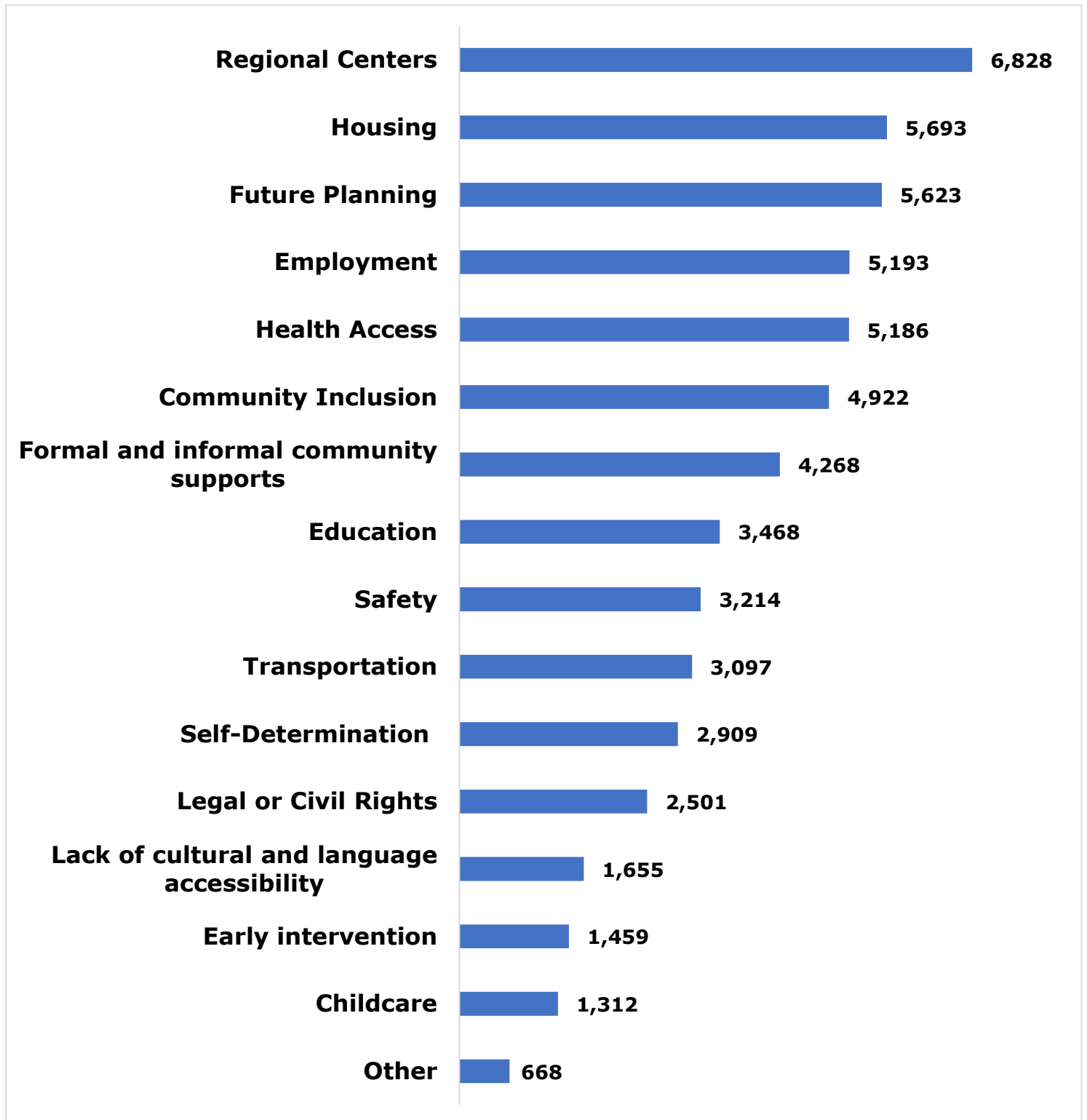**This page is left intentionally blank.**

GOAL 2

SYSTEMS CHANGE

SYSTEMS CHANGE

Question: Within California's service systems, where are the most impactful barriers for people with intellectual and/or developmental disabilities and their families?

Most Impactful Barriers (all Respondents)

Barrier	Value
Regional Centers	6,828
Housing	5,693
Future Planning	5,623
Employment	5,193
Health Access	5,186
Community Inclusion	4,922
Formal and informal community supports	4,268
Education	3,468
Safety	3,214
Transportation	3,097
Self-Determination	2,909
Legal or Civil Rights	2,501
Lack of cultural and language accessibility	1,655
Early intervention	1,459
Childcare	1,312
Other	668

Top 10 Most Impactful Barriers (by Group)

	People with I/DD	Family Members	Others
1	Health access	Regional Centers	Regional Centers
2	Housing	Future planning/transition to adulthood	Housing
3	Employment	Housing	Employment
4	Regional Centers	Community inclusion	Health access
5	Formal and informal community support	Health access	Transition to adulthood/future planning
6	Transportation	Employment	Community inclusion
7	Community Inclusion	Formal and informal community support	Formal and informal community support
8	Safety	Education	Transportation
9	Transition to adulthood/future planning	Safety	Safety
10	Self-Determination	Self-Determination	Education

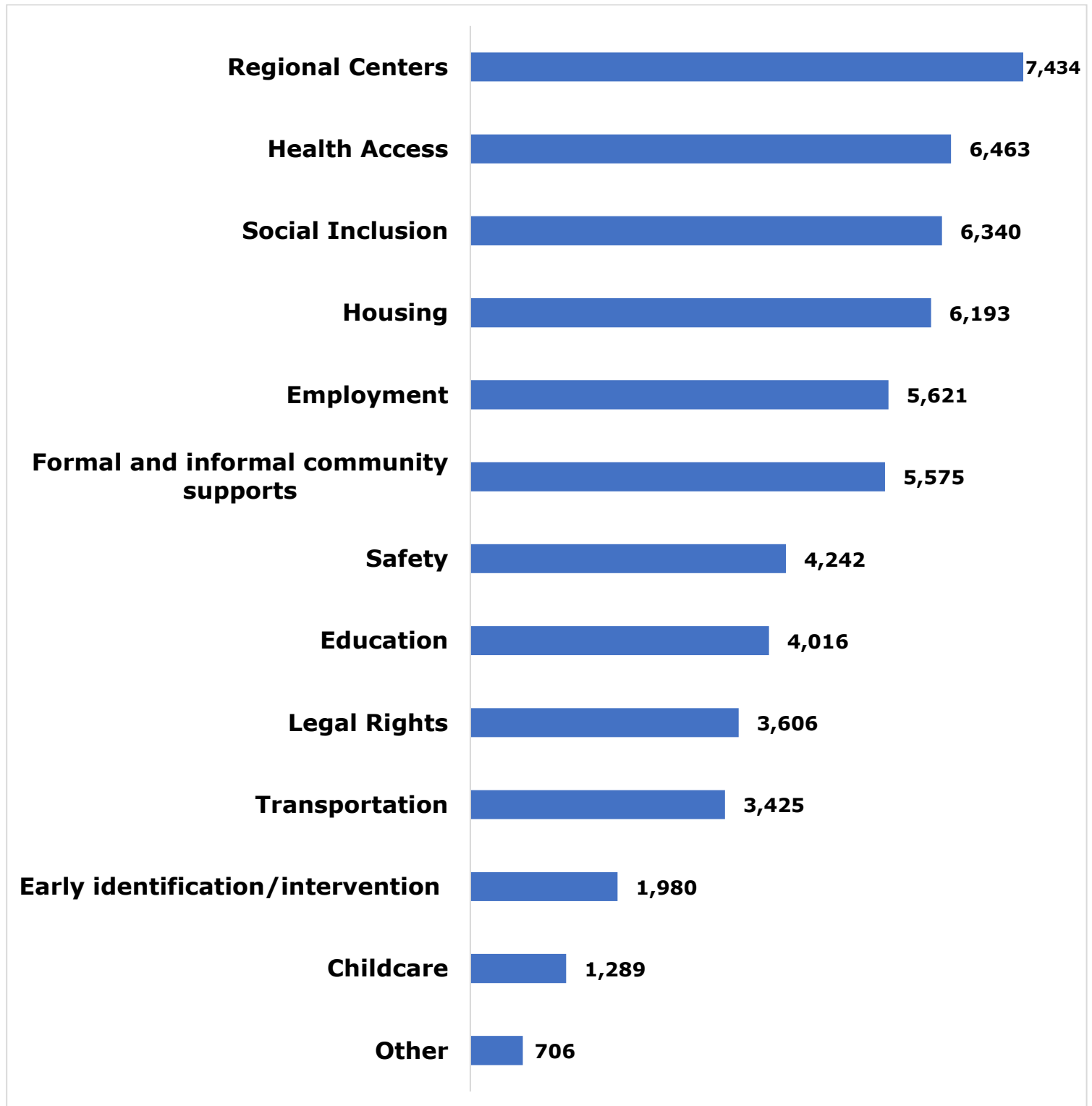**This page is left intentionally blank.**

GOAL 3

CAPACITY-BUILDING

CAPACITY-BUILDING

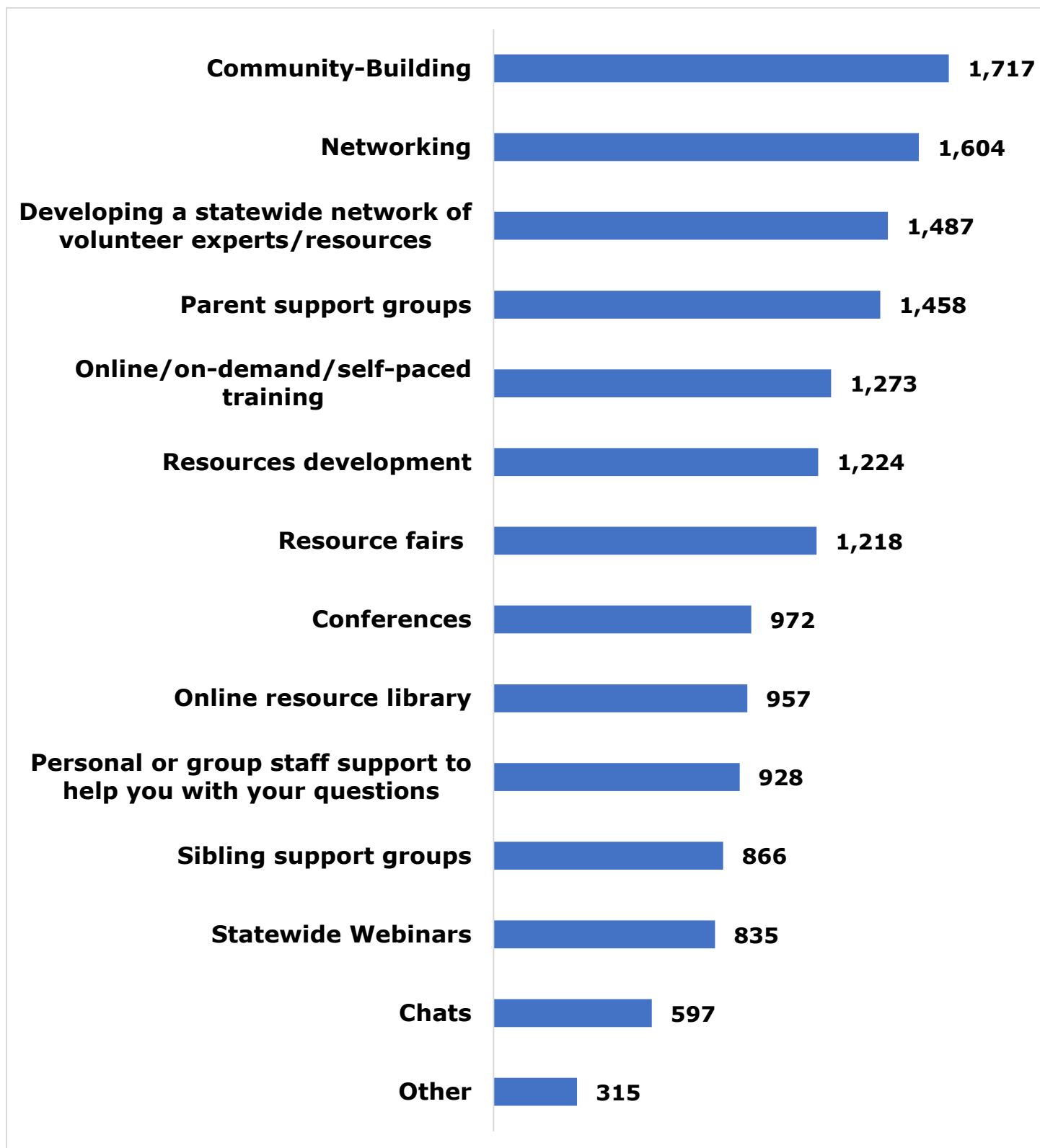| Question:	SCDD plans to build projects statewide and support communities. What are the top 5 highest areas of need?

Highest Impact Areas of Need (all Respondents)

Area	Value
Regional Centers	7,434
Health Access	6,463
Social Inclusion	6,340
Housing	6,193
Employment	5,621
Formal and informal community supports	5,575
Safety	4,242
Education	4,016
Legal Rights	3,606
Transportation	3,425
Early identification/intervention	1,980
Childcare	1,289
Other	706

Top 10 Areas of Need (by Group)

	People with I/DD	Family Members	Others
1	Health Access	Regional Centers	Regional Centers
2	Housing	Social inclusion	Housing
3	Employment	Health Access	Employment
4	Regional Centers	Formal and informal community support	Social inclusion
5	Safety	Housing	Formal and informal community support
6	Social inclusion	Employment	Transportation
7	Formal and informal community support	Education	Safety
8	Legal rights	Safety	Education
9	Transportation	Legal Rights	Legal rights
10	Education	Transportation	Early Identification/Intervention

Most Requested Activities (all Respondents)

Activity	Value
Community-Building	1,717
Networking	1,604
Developing a statewide network of volunteer experts/resources	1,487
Parent support groups	1,458
Online/on-demand/self-paced training	1,273
Resources development	1,224
Resource fairs	1,218
Conferences	972
Online resource library	957
Personal or group staff support to help you with your questions	928
Sibling support groups	866
Statewide Webinars	835
Chats	597
Other	315

Top 10 Requested Activities (by Group)

	People with I/DD	Family Members	Others
1	Community Building	Community-Building	Community-Building
2	Networking	Parent support groups	Networking
3	Resource Fairs	Networking	Developing a statewide network of volunteer experts/resources
4	Developing a statewide network of volunteer experts/resources	Developing a statewide network of volunteer experts/ resources	Parent support groups
5	Conferences	Online, on-demand, or self-paced trainings	Resource development
6	Resource development	Resource development	Online, on-demand, or self-paced trainings
7	Online, on-demand, or self-paced trainings	Resource Fairs	Resource Fairs
8	Online resource library	Sibling Support Groups	Personal or group staff support to help answer your questions
9	Parent support groups	Online resource library	Online resource library
10	Chats	Conferences	Conferences

Most Requested Resources (all Respondents)

Resource	Count
Accessing generic services/supports	1,038
Types of living arrangements	968
Mental health services and supports	954
Finding local supports	948
Future planning	927
Decision-making skills	757
Relationship skills	745
Participation in community	730
Accessing quality healthcare	729
Accessing RC services	659
Legal services/representation	633
Parenting education	565
Alternatives to conservatorship	493
Engaging w/ law enforcement/first...	474
Emergency preparedness	432
Training on history of I/DD rights	425
Understanding & utilizing civil rights	398
Abuse prevention	398
Using assistive technology	391
Sex education	377
Leadership training	306
Voting	208
Public speaking opportunities	202
How to terminate a conservatorship	160
Other	141

Top 10 Requested Resources (by Group)

	People with IDD	Family Members	Others
1	Decision-making skills	Accessing generic services and supports	Mental health services and supports
2	Mental health services and supports	Types of living arrangements	Accessing generic services and supports
3	Future planning	Finding local supports	Finding local supports
4	Relationship skills	Future planning	Types of living arrangements
5	Types of living arrangements	Mental health services and supports	Future planning
6	Accessing generic services and supports	Accessing quality healthcare	Relationship skills
7	Participation in community	Participation in community	Decision-making skills
8	Finding local supports	Legal services	Accessing quality healthcare
9	Training on the history of I/DD rights	Relationship skills	Accessing RC services
10	Leadership training	Accessing RC services	Legal services /representation

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QUALITATIVE

ANALYSIS

QUALITATIVE ANALYSIS

Question: Are there any new issues or problems that SCDD should know about? *(329 responses)*

Top Themes

1. **Services and Supports** (30–35%)

   a.   Difficulty accessing care coordination and/or regional center, IHSS, and/or respite services

   b.   Long waitlists, inconsistent information, and complex processes

   c.   Caregiver burnout caused by having to navigate through multiple systems

2. **Workforce (25–30%)**

   a.   Shortage of trained personnel, such as direct support professionals (DSPs), in-home caregivers, behavioral specialists, and/or school staff

   b.   Low staff wages and high turnover

3. **Housing (20–25%)**

   a.   Lack of affordable, accessible, and supportive housing options for adults with I/DD

   b.   Risk of homelessness risks or lack of placement without family/caregiver

4. **Access to Health and Mental Health Services (20%)**

   a.   Difficulty finding qualified healthcare providers with I/DD experience/knowledge

   b.   Significant gaps in mental health services, including crisis care, bilingual providers, and trauma-informed supports

   c.   Limited dental and preventative care access

5. **Transportation (15–18%)**

   a.   Inadequate accessible transportation for work, school, medical appointments, and community life

   b.   Issues are especially prominent in rural areas.

6. **System Navigation and Bureaucracy (15%)**

   a.   Service systems are overwhelming, inconsistent, and difficult to navigate

   b.   Excessive paperwork

   c.   Unclear guidance

QUALITATIVE ANALYSIS (Continued)

Additional Issues

1. **Post-Pandemic Regression and/or Isolation**

   a. COVID-19 service/program/social disruptions

   b. Loss of social skills, employment progress, and mental health stability

   c. Increased isolation due to loss of community programs

2. **Aging Caregivers and Future Planning**

   a. What will happen to adult/minor child(ren) if/when parents/guardians are no longer able to provide care?

3. **Digital Barriers and Technology/AI Concerns**

   a. Digital portals

   b. Telehealth platforms

   c. AI and/or automated systems are not all accessible to people with disabilities

4. **Cultural and/or Language Gaps**

   a. Services

   b. Translations

   c. Culturally responsive providers

5. **Education and Transition**

   a. Staffing shortages for special education classes/services

   b. Inadequate implementation of IEPs

   c. Poor transition planning from school to adulthood

6. **Emergency Preparedness and Safety**

   a. Lack of disability-inclusive disaster planning

   b. Fear of negative interactions with law enforcement and/or other first responders

QUALITATIVE ANALYSIS (Continued)

> **Question:** Are there ongoing or old issues that have still not been fixed?
> *(310 responses)*

Top Themes

1. **Regional Centers** (30–35%)

   a. Inconsistent services across regions

   b. High caseload numbers

   c. Frequent staff turnover

   d. Lack of communication

   e. Denial of services

   f. Many noted that these issues have persisted for years without meaningful improvement

   g. Self-Determination Program barriers

      1) Uneven implementation across the state/regional centers

      2) Lack of FMS/consultants

      3) Struggles in getting budget approvals

   h. Lack of accountability—issues are repeatedly discussed year after year, but families feel there is no enforcement or follow-through

   i. Paperwork burden and bureaucratic delays, described as emotionally draining and difficult to sustain

2. **Access to Services and/or Navigating Systems** (25–30%)

   a. Navigating systems

      1) IHSS

      2) Medi-Cal

      3) Respite

      4) SDP

      5) Other systems

QUALITATIVE ANALYSIS (Continued)

Top Themes (Continued)

2. **Access to Services and/or Navigating Systems** (25–30%) (Continued)

   b. Processes

   1) Slow

   2) Confusing

   3) Adversarial

   4) Unclear eligibility requirements

   5) Overwhelming paperwork

   c. Service and support disparities among:

   1) Regions

   2) Socio-economic groups

   3) Immigrants and families of color

   4) Rural/frontier communities

   5) Those with limited income

   6) Those will little-to-no English proficiency

3. **Shortages in Service and Support Workers (20–25%)**

   a. Qualified caregivers/DSPs

   b. Nurses

   c. Behavioral specialists

   d. School aides

   e. Bilingual providers

   f. Low wages and burnout contribute to instability and gaps in care

4. **Housing (18–22%)**

   a. Critical, unresolved issue for adults with I/DD and aging caregivers

   b. Long-term lack of affordable, accessible housing options

   c. Inadequate number of independent or supported living placements

QUALITATIVE ANALYSIS (Continued)

Top Themes (Continued)

5. **Healthcare and Mental Health (15–18%)**
   a. Inadequate access to primary care doctors, mental health professionals, dentists, and other specialists
   b. Professional staff lack understanding/knowledge about I/DD
   c. Crisis mental health services are insufficient
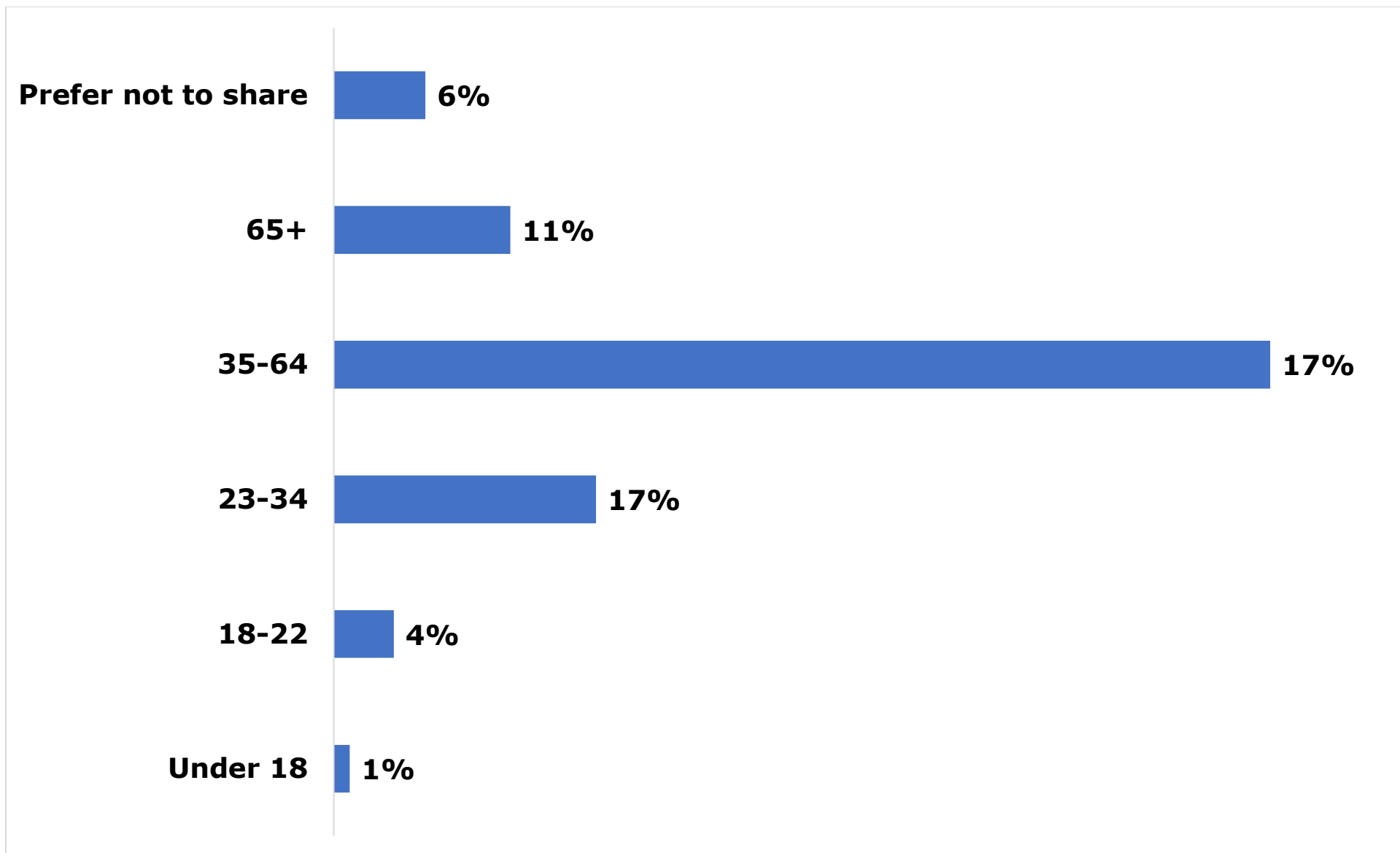   d. Long wait times
   e. Insurance barriers

6. **Transportation (10–15%)**
   a. Lack of reliable, affordable, accessible transportation
   b. Limits opportunities for:
      1) Employment
      2) Education
      3) Medical care
      4) Community participation
      5) Rural/frontier areas

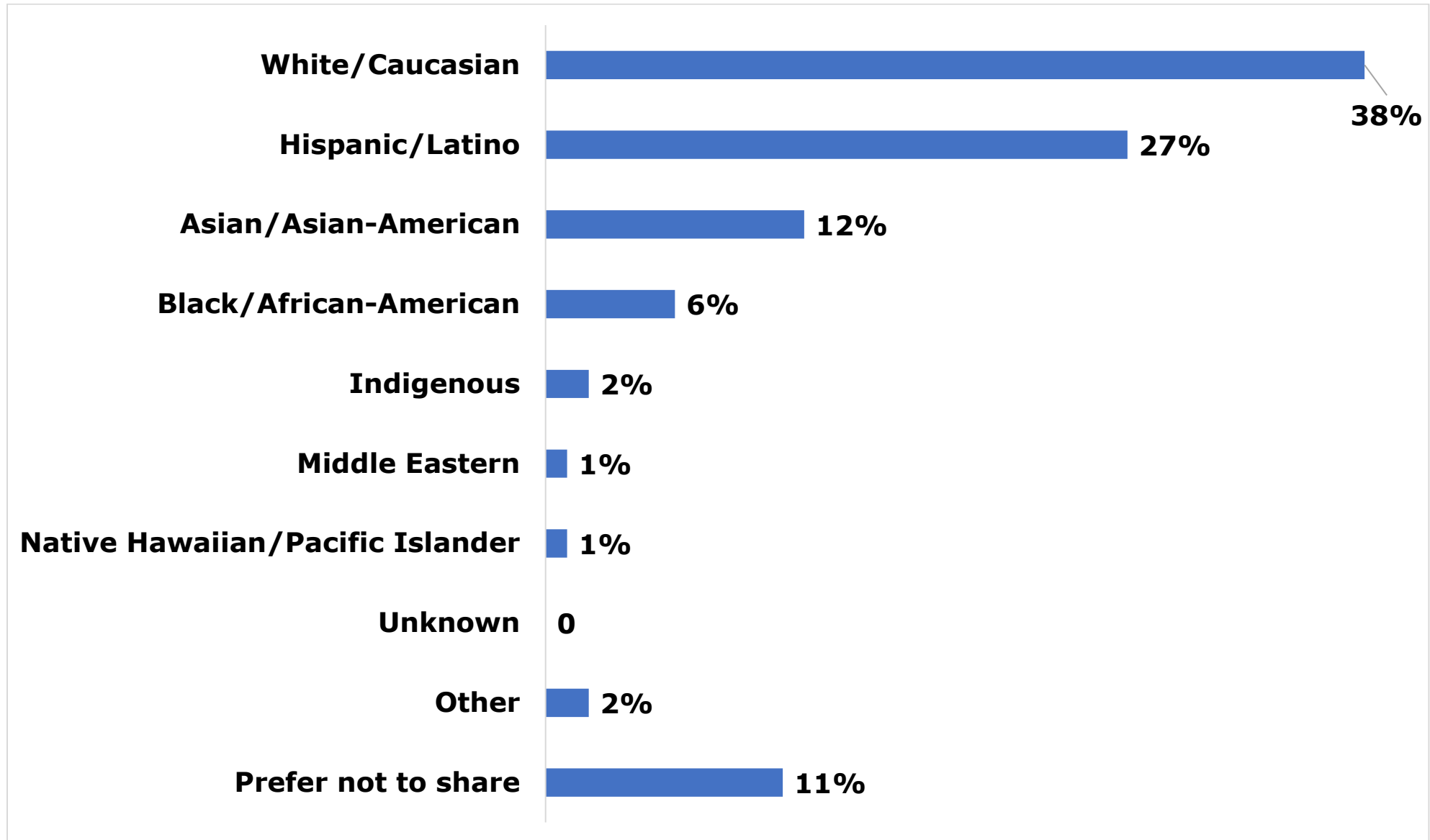# DEMOGRAPHIC DATA

Age

(2,929 responses)

Race/Ethnicity

(2,924 responses)

Race/Ethnicity	Percentage
White/Caucasian	38%
Hispanic/Latino	27%
Asian/Asian-American	12%
Black/African-American	6%
Indigenous	2%
Middle Eastern	1%
Native Hawaiian/Pacific Islander	1%
Unknown	0
Other	2%
Prefer not to share	11%

Underserved Populations

(1,317 responses)

Population	Percentage
Mental/Behavioral Health	25%
Cross-Disabilities	17%
Immigrants	15%
LGBTQ+	10%
Homeless/Unhoused	6%
Rural/Frontier	4%
Monolingual	4%
Veterans	3%
Refugees	1%
Other	25%