



2027 – 2031 STATE PLAN DEVELOPMENT

STATEWIDE SURVEY DATA ANALYSIS

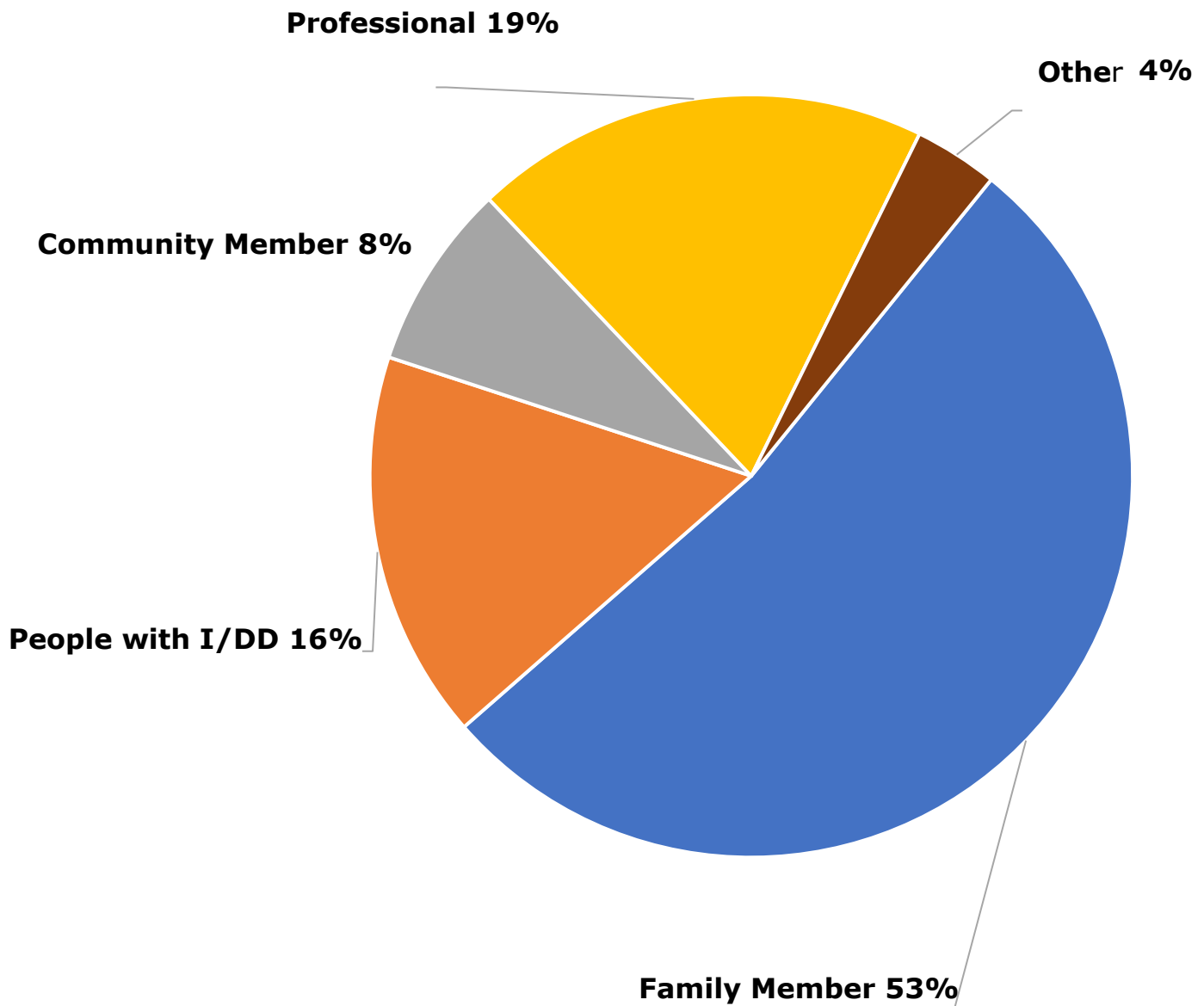
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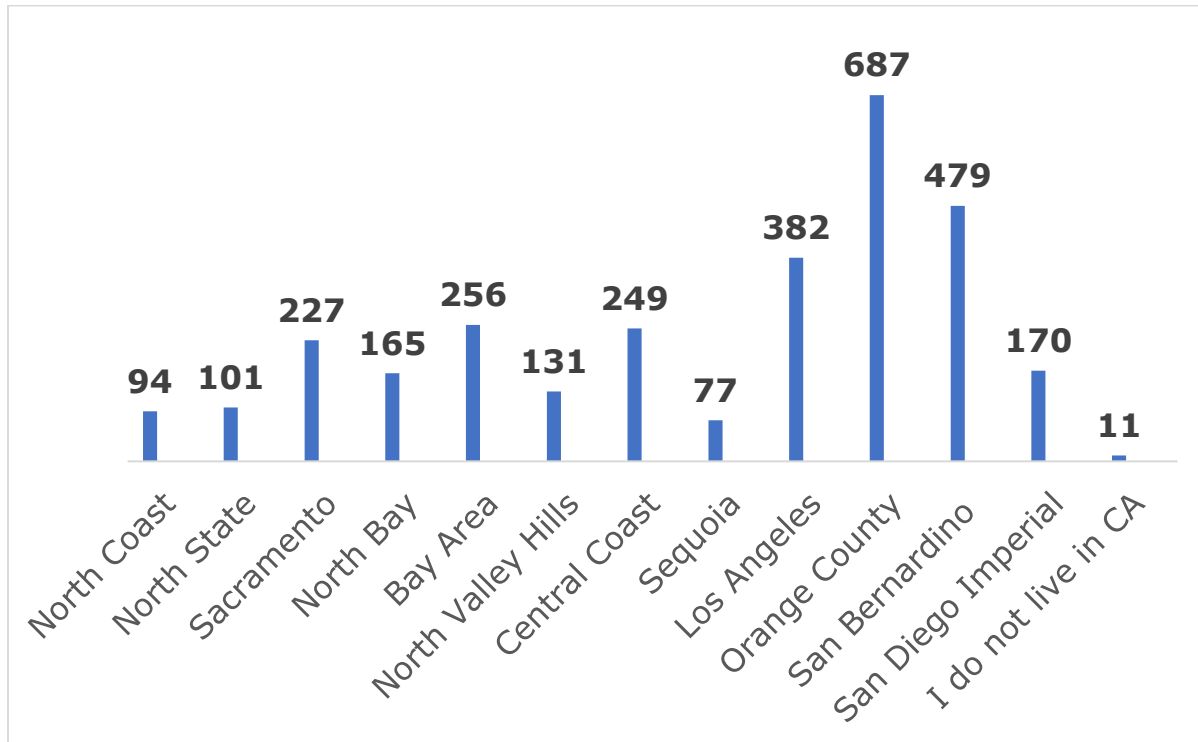
RESPONDENT OVERVIEW

Total Number of Responses: 4,197

Respondent Groups



Geographic Distribution



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

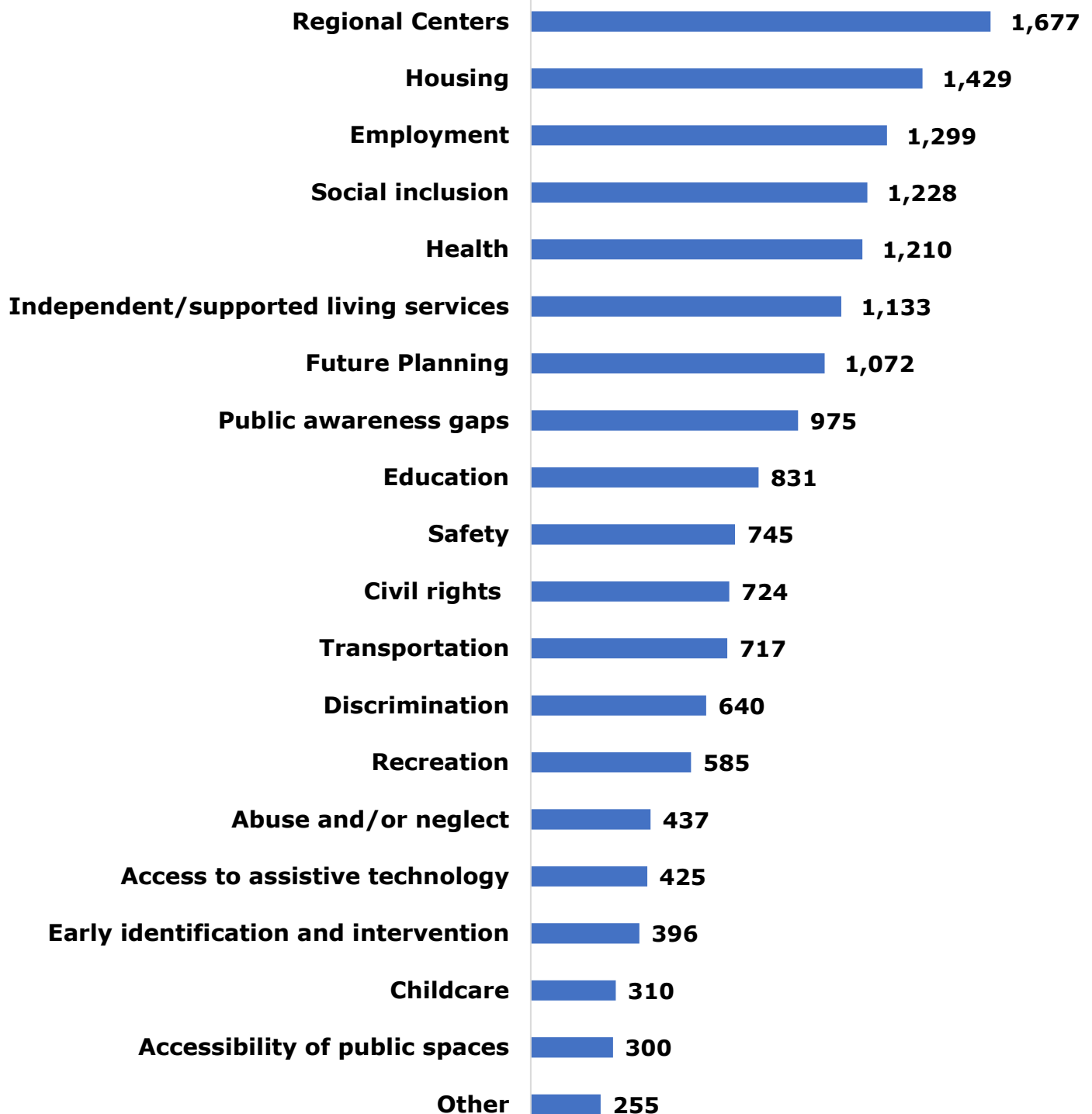
GOAL 1

SELF-ADVOCACY

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Question: What are the 5 biggest challenges facing self-advocates or people with intellectual and/or developmental disabilities?

Top Selected Challenges (all Respondents)



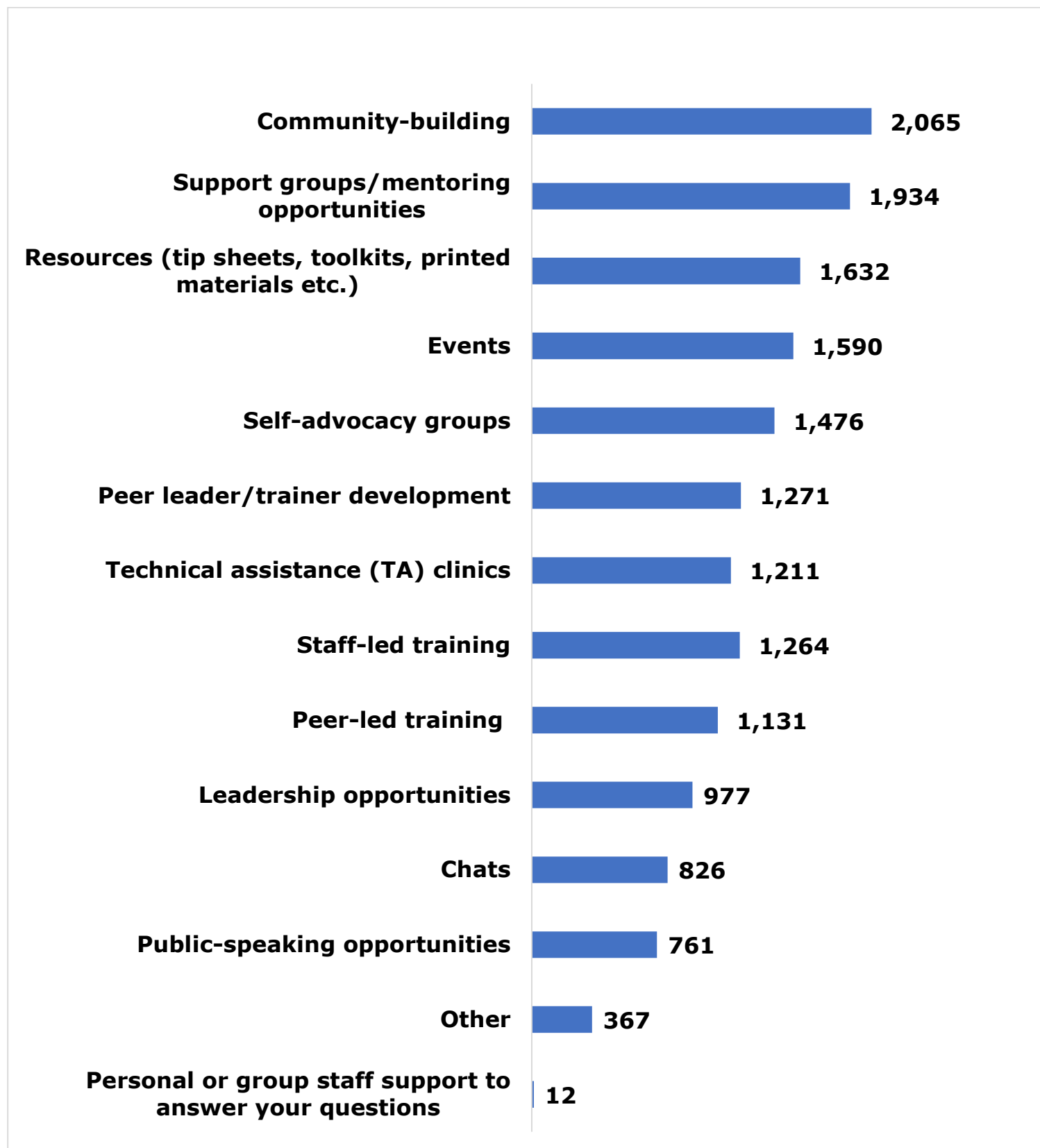
Question: What are the 5 biggest challenges facing self-advocates or people with intellectual and/or developmental disabilities? (Cont.)

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)



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

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

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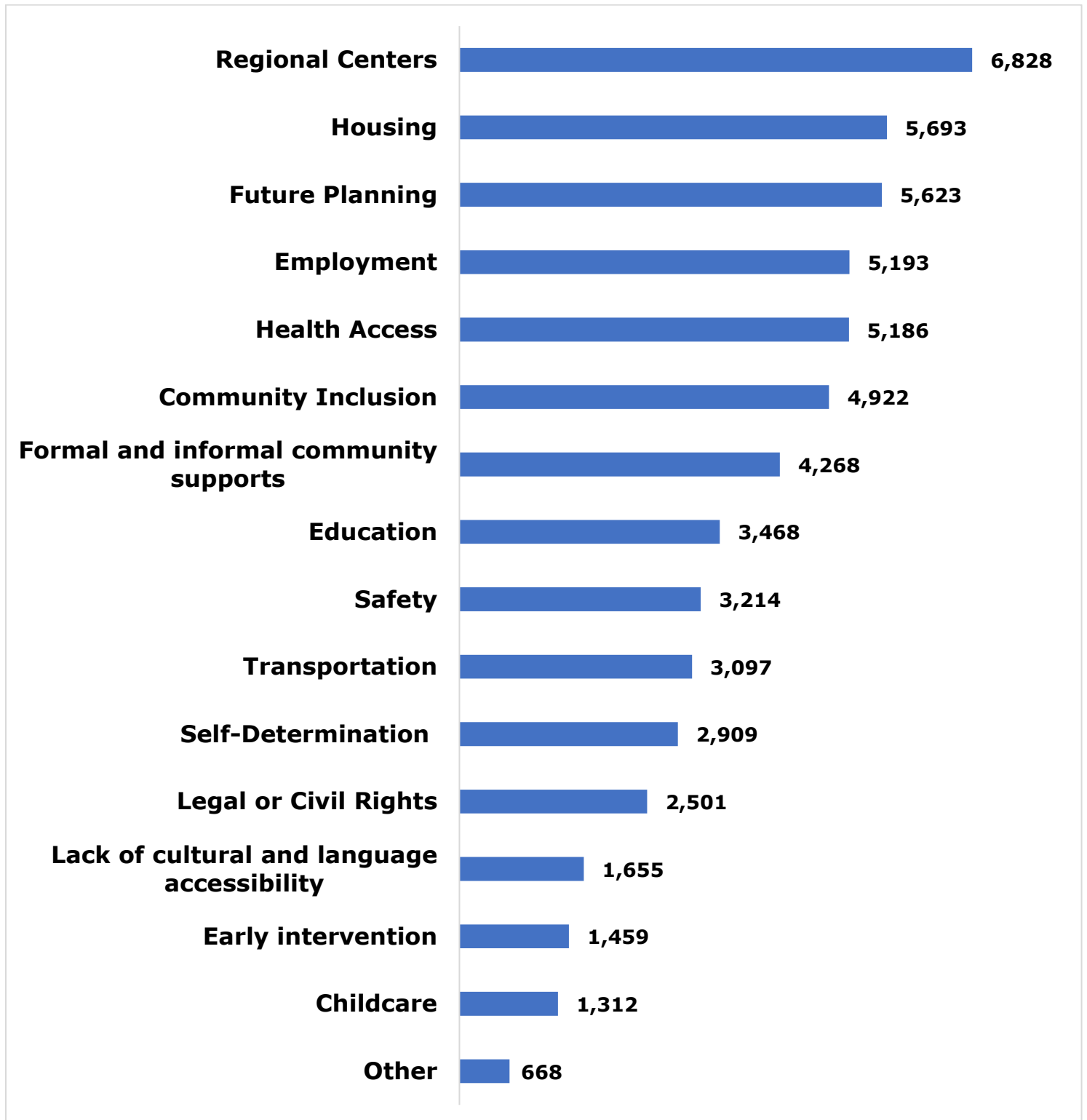
GOAL 2

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)



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

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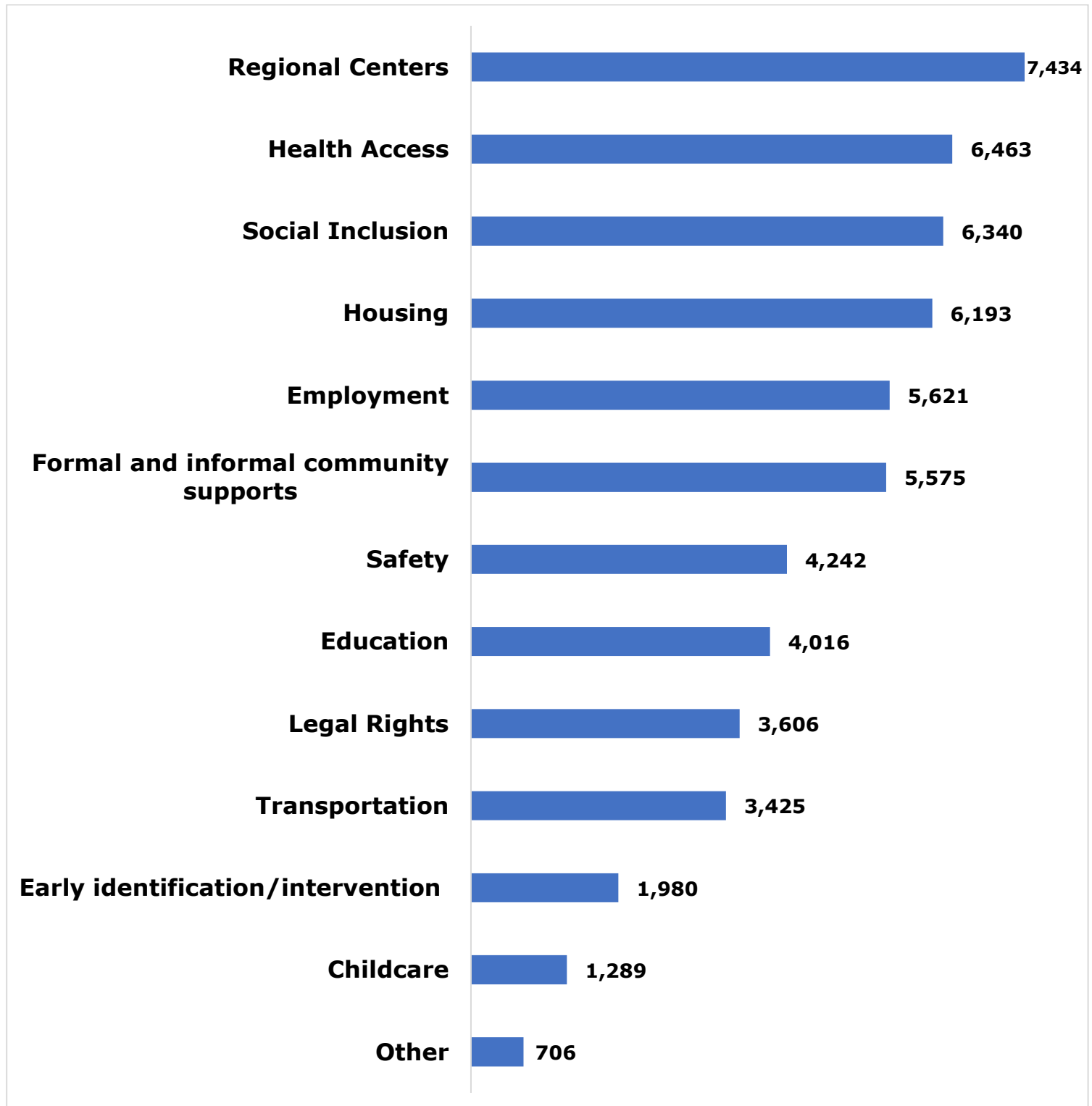
GOAL 3

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)

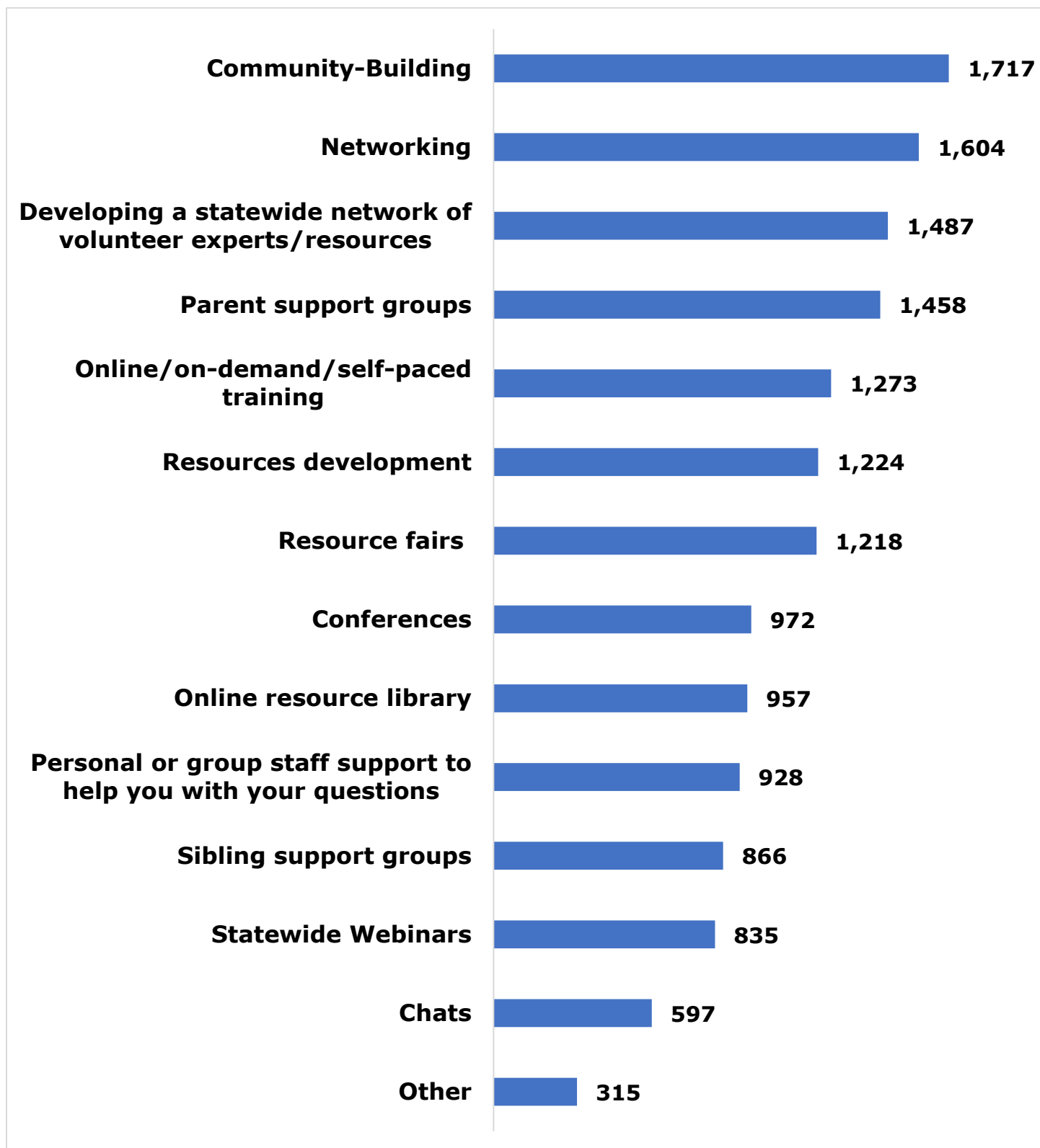


Top 10 Areas of Need (by Group)

	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

Question: What kinds of activities would be most helpful in distributing important information about services and resources to people with I/DD, their families, and those who support them?

Most Requested Activities (all Respondents)

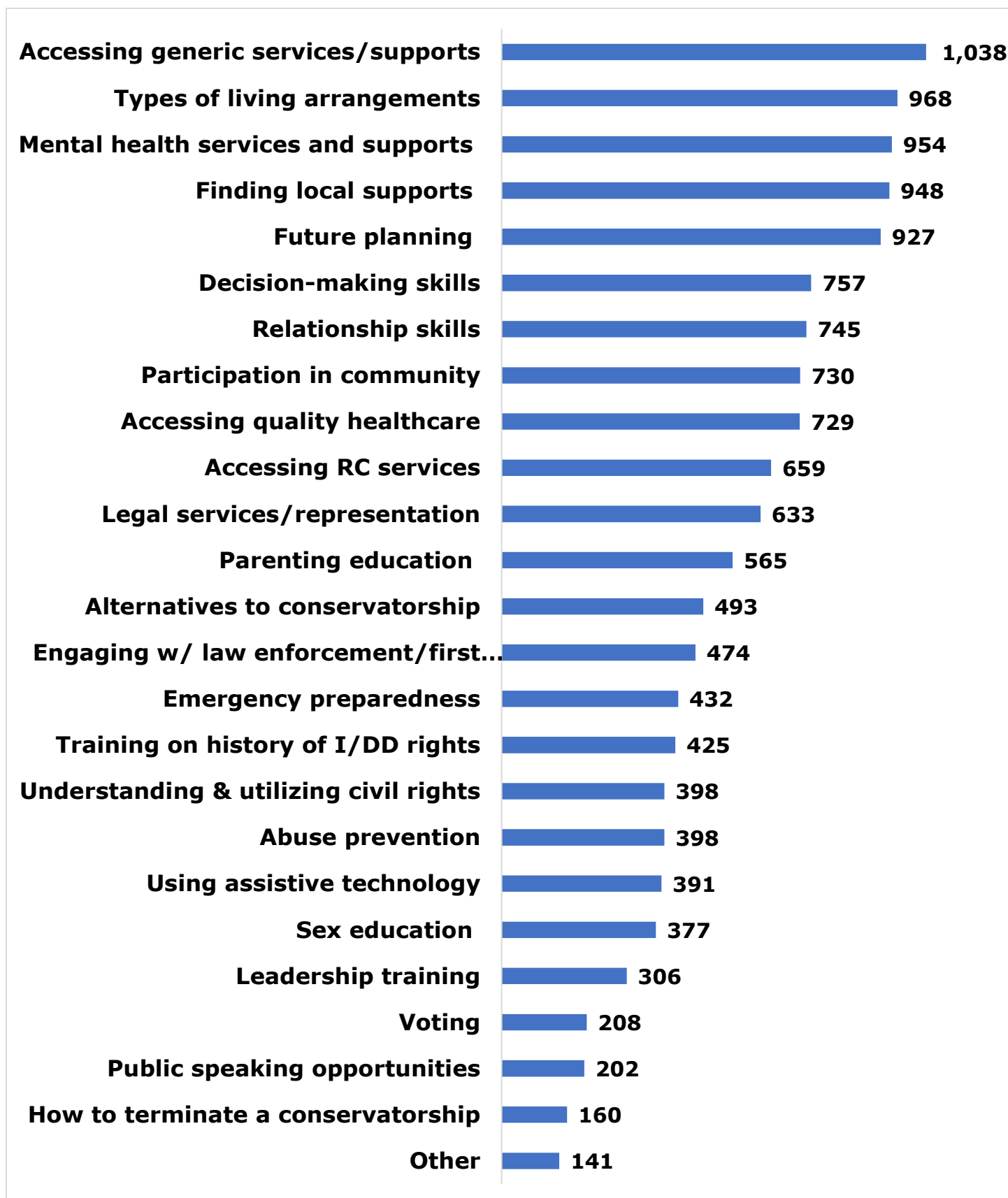


Top 10 Requested Activities (by Group)

	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

Question: What resources or support areas would make an important difference in the lives of people with intellectual/developmental disabilities and their families?

Most Requested Resources (all Respondents)



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)

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

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

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

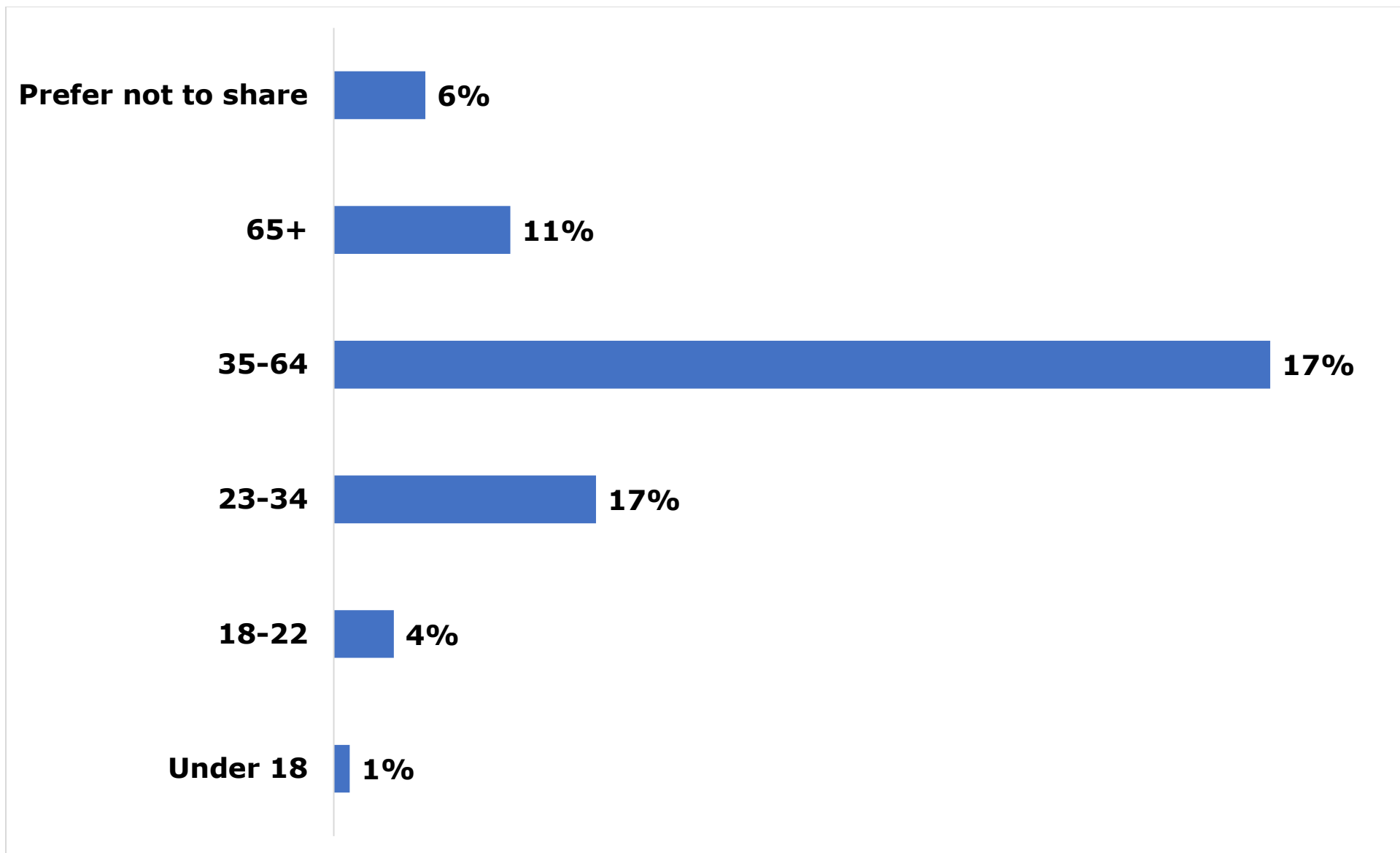
6. Transportation (10–15%)

- 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

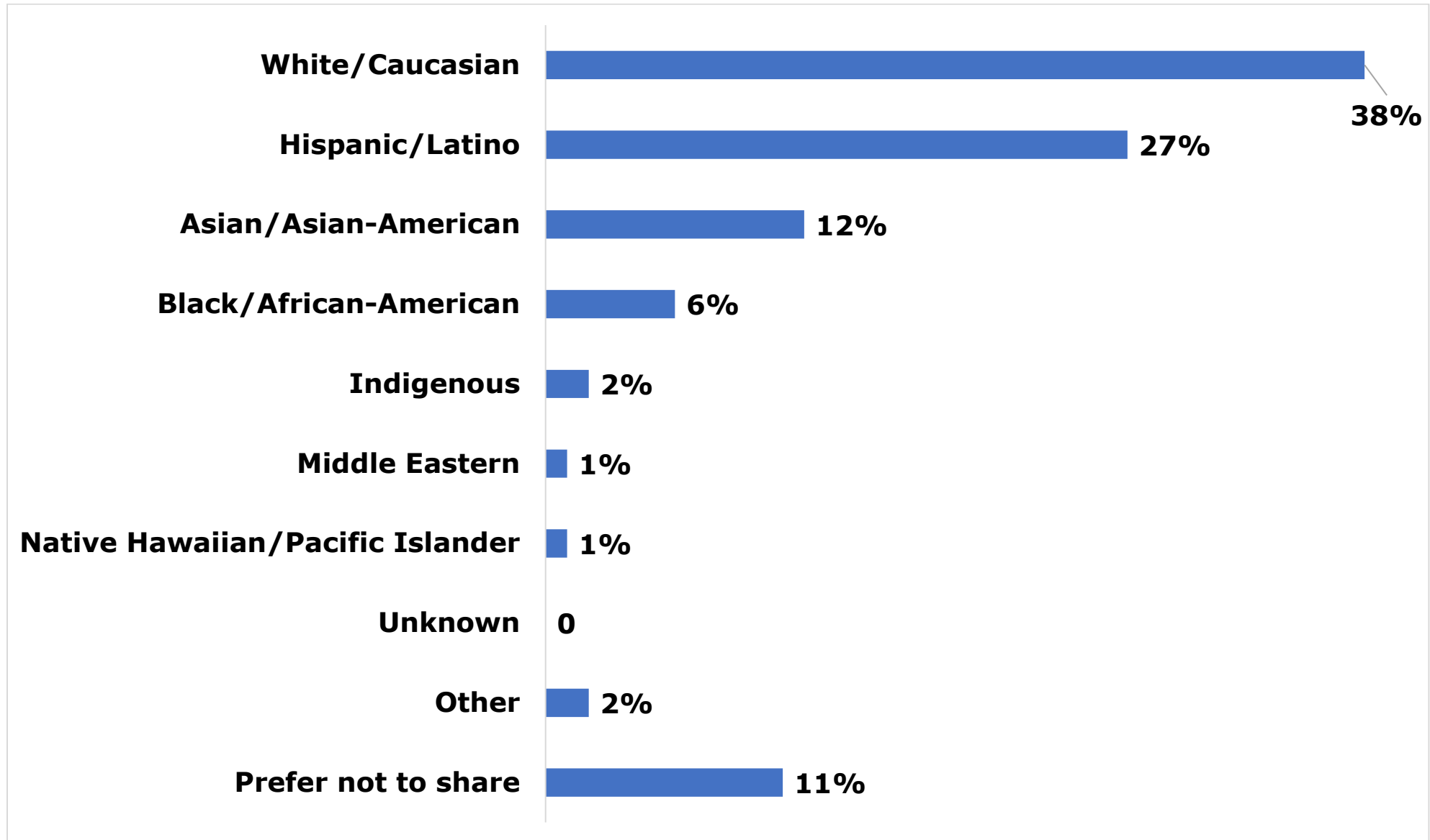
Age

(2,929 responses)



Race/Ethnicity

(2,924 responses)



Underserved Populations

(1,317 responses)

