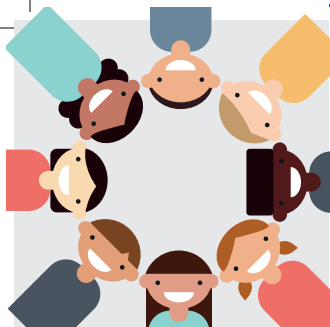




Children & Youth with Special Health Care Needs



San Francisco
Department of Public Health

Maternal, Child, & Adolescent Health Section

Summary:

71 parents and/or caregivers of children and youth with special healthcare needs participated in focus groups that were hosted by Support for Families of Children with Disabilities. Overall, participants expressed a great need for a range of community-based services to **1) support the inclusion of their children in society, school, and socio-developmental activities in the community, 2) provide caregiver relief through specialized after-school activities and childcare, 3) provide adequate housing support that accepts and values children and youth with special health care needs, and 4) provide support for parents to secure or maintain a job. Additionally, participants expressed a significant need for mental health care and respite services for themselves, their families, and their child or youth with special health care needs.** Emotion management and coping were identified as a great need for living with

special needs and/or living with a child or youth with special health care needs. Another important challenge highlighted by most participants was navigating judgmental, poorly trained, or insensitive staff in the health care and social services systems.

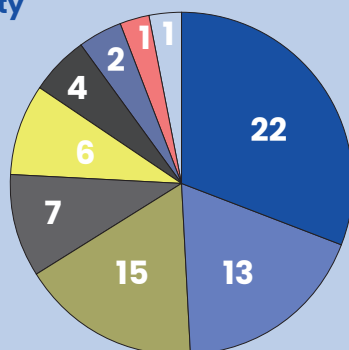
For speakers of other languages, navigating these complex systems was exacerbated by cultural and language barriers. and For Black/ African American participants, race and cultural barriers were perceived as a significant obstacles to receiving comparable services offered to children and youth with special health care needs of other races. Related to navigation services, many parents expressed challenges with referral systems, not having enough specialty providers within the system (particularly dentists), or incredibly long waitlists that impact the quality of life of the children and their families.

Demographics N=71

Community Participants' Race/Ethnicity

	Count of Race/Ethnicity
Asian	22
Hispanic/Latinx	13
African American/Black	15
White	7
Not Reported	6
Prefer not to say	4
Native Hawaiian or Other Pacific Islander	2
Do not identify with a race	1
American Indian or Alaska Native	1
Grand Total	71

Count of Race/Ethnicity



Participants' Language

	Count of Language
English	42
Chinese	16
Spanish	12
Other	1
Grand Total	71

Count of Language



Participants' Ages

	Count of Age
18-20 yrs	1
21-30 yrs	7
31-40 yrs	24
41-50 yrs	28

Participants' Ages

	Count of Age
51-60 yrs	3
61-70 yrs	2
Not Reported	6
Grand Total	71

Participants' Gender

	Count of Gender
Female	50
Male	14
Not Reported	6
Other	1
Grand Total	71

Neighborhood

Community Participants' Neighborhood	Count of Zip Code
Not Reported	22
Bayview/Hunters Point	9
Ingleside/Excelsior	7
South of Market	6
Mission District/Bernal Heights	5
Visitacion Valley	3
Sunset/Parkside/Forest Hill	3
Polk/Russian Hill/Nob Hill	2
Lake Merced/Lakeside	2
Hayes Valley/Civic Center/Tenderloin	2
Outer Richmond	2
Rincon Hill	2
Twin Peaks/Glen Park	1
Castro/Noe Valley	1
Chinatown	1
Sunset	1
Non SF Zip Codes	1
Inner Richmond/Laurel Heights	1
Grand Total	71

Top Health Issues

Topic	# times mentioned
Community Inclusion and Social Supports for the Family and their Child	123
Case Management/Navigating Complex Health Care Systems and Related Services	74
Mental Health and Respite Care for the Family/ Parent/Caregiver	55
Service quality	55
Access/Availability of Specialty Providers Including Dentists	45
Access to Care/Health Insurance	42
Mental Health of Child/Youth with Special Health Care Needs	40
Work ability (how needs impact ability for family to work)	31
School navigation and support	28
Economic/Financial	28
Racism/Discrimination/Health Equity	23
Emerging Issue/Other: Cognitive conditions	21
Referrals	17
Housing insecurity support for families' w/ children w/ special needs	17

Quotes from focus group participants'

Community Inclusion and Social Support



"We need mental health support, individual and family - especially since children with CHD's have a higher level of anxiety and depression and parents have higher levels of PTSD and depression/ anxiety."

"The mental health of my children is uncertainty since in San Francisco they do not have all the support they need."

"We have not yet found reliable childcare or afterschool/weekend/ summer programs for him."

Case Management/Navigating Complex Health Care Systems and Related Services

"Not just a place for support, but a space that helps parents navigate through different systems such as healthcare and also can give hands on help/face to face."

"Accessing services in a timely manner and without having to ask and request and fight so much for those resources ... but your thoughts are not heard until someone else comes in and supports."

"Referrals were unbelievably challenging – not taking referrals, wait times."



“Not having good childcare makes it hard for me to leave my child alone at times and not being able to work. I have to call off work to stay home and care for my kid.”