

SUMMARY REPORT - FALL 2024

Adams County Health Department & Parent to Parent of Colorado
**Family Experience Survey
for Children & Youth with
Special Health Care Needs**



PARENT TO PARENT
OF COLORADO



ADAMS COUNTY
HEALTH DEPARTMENT

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The Adams County Health Department (ACHD) Maternal Child Health team and Parent to Parent of Colorado (P2P-CO) surveyed families in Adams County with children and youth with special health care needs (CYSHCN). This survey was conducted in June 2024 and sent to parents in P2P support groups within Adams County. Parents who completed the survey were given a \$25 Amazon gift card. Eighty responses were received—66 in English and 14 in Spanish.

This report summarizes the most important data points of the survey. In addition, there are five key areas of opportunity with associated recommendations for improvement. The recommendations are based on what families shared in open-ended questions. Several questions asked caregivers what services they currently use that are helpful and what they would like to see improved. In addition, parents were asked about the

barriers they experience and how they would improve those barriers to care or services. Lastly, there were several questions about caregivers' and CYSHCN's well-being, including physical, mental, and social support, and how these aspects of their lives could be improved.

Key Areas of Opportunity:

- Simplify Medicaid waiver processes
- Improve economic support and security for families
- Provide clarity on available providers and services
- Increase mental health support for both parents and CYSHCN
- Improve on language access

Total Responses

80

English

66

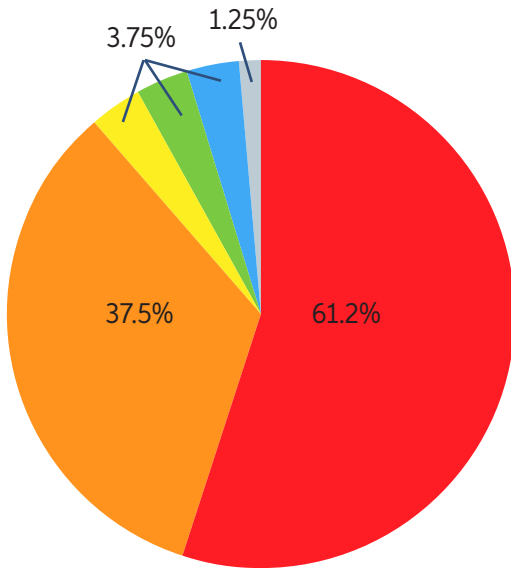
Spanish

14



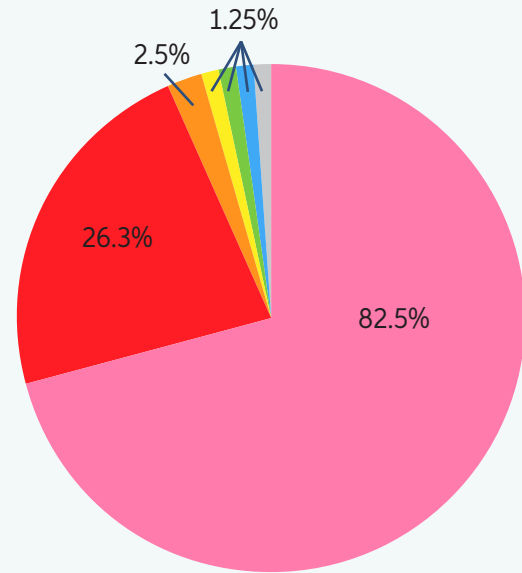
Demographics of Respondents

Race/Ethnicity



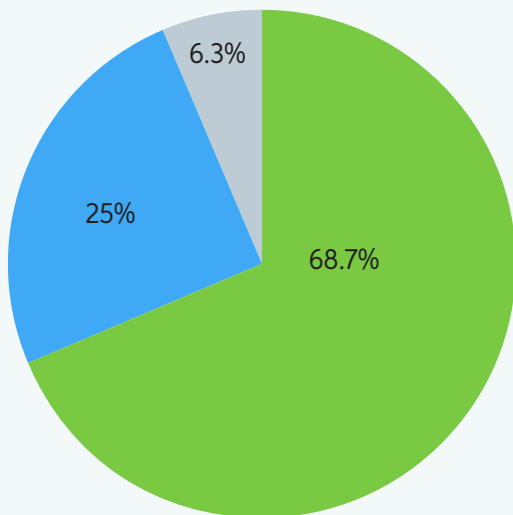
- White: 61.2%
- Asian/Asian American: 3.75%
- Hispanic/Latino: 37.5%
- Black/AA: 3.75%
- American Indian/Alaska Native: 3.75%
- Middle Eastern & North African: 1.25%

Languages Used at Home



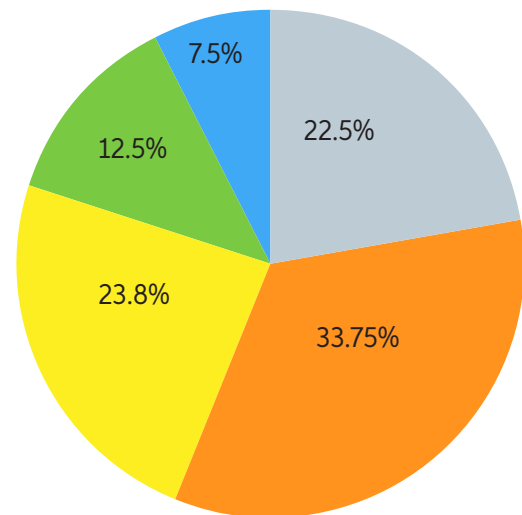
- English: 82.5%
- Spanish: 26.3%
- American Sign Language: 2.5%
- Russian: 1.25%
- Chinese: 1.25%
- Arabic: 1.25%
- Japanese: 1.25%

Number of CYSHCN in Household



- 68.7% had one child with a special healthcare need
- 25% had two children
- 6.3% had three or more children

Ages of CYSHCN



- Age 0-5: 22.5%
- Age 15-17: 12.5%
- Age 6-10: 33.75%
- Age 18+: 7.5%
- Age 11-14: 23.8%

Insurance

- Over half (55%) of respondents have Medicaid for their CYSHCN because they qualify financially, or through the Medicaid buy-in program.
- 32.5% of respondents have a child or adult Medicaid waiver through a single-entry point or a case management agency.
- 37.5% of respondents have insurance through a current or former employer or a union.

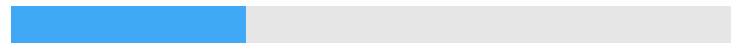
All children of the respondents have insurance. However, ACHD is aware that many children in Adams County do not have insurance and are, therefore, not eligible for certain coverages and services.

Two of the insurance-related questions asked respondents what aspects of their child’s health insurance they were happy with and which aspects they wished were better. In this chart, the English and Spanish results are aggregated. The only disparity in responses was about the cost of insurance.

55% Have Medicaid for CYSHCN



32.5% Have a Medicaid waiver

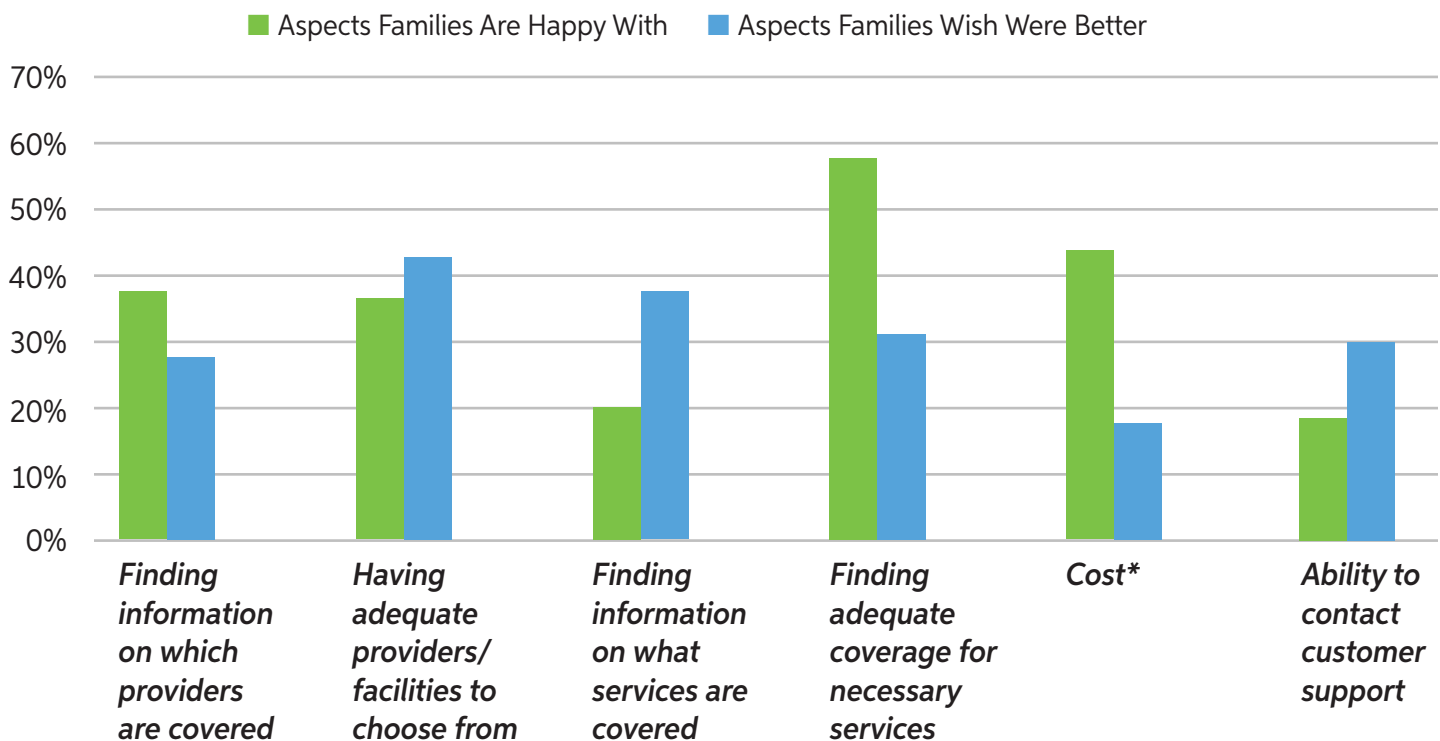


37.5% Have insurance through their employer



[I need more] knowledge of what services are available for my children. We usually don't know about services until we no longer need them."

Insurance Aspects Families are Happy With and Wish Were Better



*Thirty-four of the 66 English-speaking respondents were happy with the insurance cost. However, only one of the 14 Spanish-speaking respondents was pleased.

Thirty-four out of the 66 English-speaking respondents were happy with the insurance cost. However, only one of the 14 Spanish-speaking respondents was pleased with the cost. Of the 32.5% of respondents who indicated that their child receives insurance through a Medicaid waiver, many noted a lack of available providers for covered services, namely respite and home care services. Respite care is short-term care provided for CYSHCN caregivers so that they may take a break from caregiving duties. Respite care can be provided in-home or in a facility by caregivers and is paid for under several HCBS (Home and Community-Based Services) Medicaid Waiver programs.

Other sources of dissatisfaction included long wait times for waiver approval, confusion around eligibility criteria and covered services, logistical hiccups with approval and renewal processes, and insufficient communication with case managers and service coordinators.

Policy Recommendations:

- Incentivize more providers to accept Medicaid so there are more providers and services to choose from
- Increase Medicaid reimbursement for providers
- Simplify waiver processes



Self-rating of Financial Security

In total, 33.7% of respondents said they live paycheck to paycheck and are unsure if they can pay all their monthly bills. Many families of CYSHCN are struggling financially due to the cost of insurance, inability to afford necessities for their child because they are not covered by insurance (i.e., therapies, ceiling lifts, etc.), and housing. However, there was a disparity between English- and Spanish-speaking respondents. Fifty percent of Spanish-speaking respondents said they were living paycheck to paycheck, and 30.3% of English-speaking respondents said the same.

Economic Security Recommendations:

- Increased tax credits for families of CYSHCN
- Financial assistance for childcare and transportation/gas
- More affordable insurance copays

“[We need] more providers throughout the entire Denver metro area. There are too few close to us that accept our insurance, so we have to drive significant distances for services.”

Barriers to Obtaining Services and Supports

Respondents faced many different barriers when obtaining services and supports for the health and well-being of their children. However, there were very different answers for English respondents compared to Spanish respondents.

Over 25% of English-speaking respondents said barriers to obtaining services or supports for their child included

getting time off work, not knowing how to find a provider or being unsure of what services exist, and difficulty scheduling or lack of appointment availability. Additionally, they had concerns about their child having excessive absences at school or the school not being supportive.

In contrast, over 25% of Spanish-speaking respondents said the cost associated with health insurance copays, difficulty navigating insurance benefits, and the lack of language access were the most common barriers to accessing services or supports for their child.

Both English- and Spanish-speaking respondents noted that transportation was also a barrier to obtaining services and supports. Many of the available services in the Metro area are not located in Adams County and families have to travel across the city to access them.

Provider Recommendations:

- Evenings and weekend appointment availability
- More providers who accept Medicaid
- More navigators for patients/clients
- Training for providers to better understand the barriers families face with children with complex care needs
- Childcare for siblings during appointments
- Clarity from providers about when siblings are allowed to attend appointments

Communication & Website Recommendations:

- Insurance providers/waiver providers
 - Ability to contact customer support
 - Call wait times are long and getting connected to a person is very difficult
 - Clear information on which providers are covered
 - Clear information on what services are covered
 - Easier way to schedule appointments (either online, phone, or through an app)
 - Clear guidelines on waiver processes

Mental Health & Social Support

Most English- and Spanish-speaking respondents said they were very likely (39%) or somewhat likely (29%) to reach out to professional or community organizations for emotional support. However, the most common answers as to why respondents would not seek emotional support from a professional were due to the cost, not being able to find a provider, or lack of childcare.

When asked how often respondents engage in activities or connect to social supports that help them feel supported or connected to others who understand their situation, 48.7% of respondents engage in such activities at least once a month. However, 35% said they do this only once a year to a few times a year, and 16% said they never engage in these activities. Lack of time, childcare, respite care, finances, and a lack of a social support network were the main reasons people did not engage in these activities.

Family Support Recommendations:

- Better access to respite care options
- More resources in Spanish
- Parent support groups in the north metro area
- Better communication about what services are available for caregivers
- Mental health therapists who take a variety of insurance providers

When asked how often families of children with special health care needs engage in activities they enjoy, such as sports, hobbies, spending time with friends, etc., 68.8% of CYSHCN engage in these activities once a month or more frequently. In contrast, 31.25% engage in these activities less often, and 13.75% never do. Finances, lack of a social network or support, and lack of accessibility were the main reasons why CYSHCN do not engage in activities as often as they'd like.

Despite many challenges and much room for improvement, many organizations support and provide resources to CYSHCN families. Below is a sample of some of the organizations respondents receive information and resources from regularly:

- ARC of Adams County
- Colorado Hands and Voices
- HopeKids Colorado
- Parent to Parent of Colorado
- Rocky Mountain Down Syndrome Association
- Autism Speaks
- El Grupo Vida
- Cultivando
- Familias Especiales
- Cromosoma Del Amor

“Se necesita mas personal calificado para trabajar con niños especiales porque por eso no hay tantas citas disponibles.”

“More qualified people are needed to work with children with special needs, that’s why there are so few appointments.”

“Que haya más información de los recursos que existen y sobre todo en el idioma.”

“More information is needed about available resources, especially in Spanish.”

Adams County Health Department and Parent to Parent of Colorado would like to **express our appreciation for the families who participated in this survey** that will help us improve the care landscape for CYSHCN families. We would also like to **thank the wonderful list of organizations that provide support.**

“Our providers through Early Intervention (physical and occupational therapy) have been extremely helpful in sharing resources and offering tons of support for our family.”



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303.220.9200