

Children and Youth with Special Health Care Needs: Landscape Scan

PREPARED FOR DOUGLAS COUNTY HEALTH DEPARTMENT

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Table of Contents

Table of Contents	2
Executive Summary	3
Introduction	7
Methodologies	7
A Snapshot of CYSHCNs in Colorado and Douglas County	11
Summary of Community Provider and Caregiver Focus Group Findings	19
What is Working Well in Douglas County	19
Priority Areas for CYSHCNs	21
What is Not Working Well in Douglas County	25
Building Awareness of Services and Supports for CYSHCNs	
Community Collaboration	35
Opportunities for Douglas County Health Department	
Appendix A: Community Key Informant Guide	
Appendix B: Caregiver Focus Group Discussion Guide	42
Appendix C: Caregiver Survey	44
Appendix D: Community Meeting PowerPoint Slides (Attachment)	49

Executive Summary

The Douglas County Health Department (DCHD) engaged Health Management Associates, Inc. (HMA), a national research and consulting firm with an office in Colorado to conduct a community landscape scan focused on existing resources and resource gaps for Children and Youth with Special Health Care Needs (CYSHCNs) and their families. This assessment explored the barriers and facilitators to accessing community resources for Douglas County CYSHCNs and their families. DCHD will use the assessment findings to inform strategies to achieve the goal that all children, youth, and families in Douglas County are valued, healthy and thriving. Three approaches were used to inform the landscape scan: community provider key informant groups; focus groups with caregivers of CYSHCNs; a survey of caregivers of CYSHCNs; and a community meeting for community provider organizations and caregivers.

What is Working Well

There was a sense that when families are connected to services, it is a positive experience. The support of family and friends has been a significant factor in their success, with some reporting their children are doing better in school and making friends. The proximity of medical facilities has also been helpful for accessing necessary care.

School-based Support

- Implementation of inclusive policies and practices that support the educational success of CYSHCNs
- Strong partnerships with hospitals, for example, to implement Sources of Strength, a best practice youth mental health promotion and suicide prevention program
- Professional development occurring in schools regarding trauma-informed practices and approaches, and restorative practices

Community-based Support

Douglas County has a variety of community resources and organizations – such as Developmental Pathways, the ARC of Colorado, the Special Olympics, and the Children's Hospital Colorado, which has a clinic in Highlands Ranch

Inclusive Parks and Recreation

- Douglas County created inclusive parks and recreation programs that are accessible and welcoming to CYSHCNs
- The County built several playgrounds and facilities that are designed to accommodate children with disabilities

Priority Areas for CYSHCNs

"Improve access to support" was the top priority selected by both community providers and caregivers, followed by "increase social emotional well-being". "Creating safe and connected built environments and "promoting positive youth development" were both a third priority.

Major Health, Development, and Well-being Issues for Caregivers and CYSHCNs

Below is a summary of the major health development and well-being issues affecting CYSHCNs and their caregivers in Douglas County. These include:

- *Limited Access to Care:* The word most used by both caregivers and key informants about accessing care was "frustrating". Various barriers, including limited access to specialty care, challenges in care coordination, lack of awareness about available services and supports, transportation barriers, and language and cultural barriers were all noted as challenges for CYSHCNs and their caregivers.
- *Physical Health Issues*: CYSHCNs may have chronic medical conditions, such as asthma and diabetes, that require ongoing medical management and treatment. It was noted as a challenge for some to even get the physical health care a child needs due to a lack of providers, eligibility, affordability, and proximity.
- Social Isolation: CYSHCNs may experience social isolation or difficulty making friends due to their condition or limited opportunities for socialization, and was a common challenge expressed among caregivers.
- *Caregiver Stress:* Caring for a CYSHCN can lead to increased levels of stress, anxiety, and depression among caregivers. The emotional and mental well-being of caregivers should be a priority to ensure they can provide optimal care and support for their children. Caregivers spoke to a need for their own opportunities for connection with other caregivers of CYSHCNs, and the positive impact support groups can have for them.
- *Financial Stress*: The costs associated with caring for a CYSHCNs can be significant and may cause financial strain for families. Frequently, caregivers expressed challenges with affordability of services, such as childcare, and health care.
- *Need for more caregiver education and support:* Often, there is a focus on educating CYSHCNs, but caregivers also expressed a need for education and support to better understand their child's needs and navigate the system of care. Some caregivers noted that resources do exist, but it is challenging to find them. There is much reliance on word of mouth.
- *Limited communication between schools and parents:* Caregivers expressed at times feeling unheard by school staff, and there is a need to improve communication and collaboration between schools and families.
- *Mental health conditions and siloed mental health resources:* CYSHCNs may be at increased risk of developing mental health issues, such as anxiety or depression, due to stress and challenges associated with their condition. For CYSHCNs, mental health services can be fragmented and disconnected, with little coordination between providers and organizations. Also, some providers may not serve CYSHCNs. While mental health resources are already limited in Douglas County, barriers to mental health care are exacerbated for CYSHCNs.
- *Challenges with insurance and payment:* Caregivers spoke to the challenges navigating insurance and payment systems and that it is a significant barrier to accessing services.

These issues are exacerbated for families whose primary language is not English and/or families of color. Caregivers and key informants expressed that the system of care in Douglas County for CYSHCNs is different depending on these demographic characteristics.

Opportunities for Douglas County Health Department

Efforts for CYSHCNs to improve access to care, and address gaps in both caregiver supports and resources will need to involve a multi-faceted approach. This may include development of new resources while building awareness for existing resources, improving insurance coverage, expanding the availability of providers with expertise in caring for these children, improving transportation options, addressing language and cultural barriers, and improving coordination of care among providers and across different systems of care.

To address the identified challenges, key informants and caregiver input suggest a need for DCHD to:

- 1. Take a comprehensive approach involving improved communication and collaboration, training and education programs, increased access to affordable services, supportive policies, and specific support for caregivers.
- 2. Recognize the critical role of caregivers and implementing caregiver support programs. Respite care services, mental health resources, and caregiver education initiatives can significantly improve the well-being of CYSHCNs and their families.
- 3. Build awareness of available services and supports for caregivers and facilitate access to caregiver networks and support groups to provide vital resources and assistance.
- 4. Leverage the expertise of healthcare providers, schools, community organizations, and government agencies to enhance the support system for caregivers and contribute to the overall well-being of CYSHCNs through fostering greater coordination and collaboration.

DCHD plays an important role in increasing access to support for CYSHCNs in Douglas County. DCHD can collaborate with other community organizations, healthcare providers, and families to promote the health and well-being of CYSHCNs. Some of the specific ways that key informants noted that DCHD may support CYSHCNs and their families include:

LEARN

DCHD can learn from CYSHCNs and their families regarding how they want to learn about and receive services and support, and how best to meet families where they are.

BUILD AWARENESS AND SHARE INFORMATION

DCHD can provide information about available services and support, as well as guidance on eligibility requirements and how to apply for benefits. A key role it needs to play is first building trust in the community.

CONVENOR

DCHD can facilitate learning and awareness building between County departments, service providers, schools, CBOs, and other family service entities.

COMMUNITY OUTREACH

DCHD can provide community outreach and education to raise awareness about the needs of CYSHCNs and the services and support available to them.

ADVOCATE

DCHD can advocate for policies and programs that support the needs of CYSHCNs and their families, including increased funding for healthcare services and support programs to help overcome the financial stress many families are feeling or expanded service hours to better accommodate children and family's school and work schedules.

UNIVERSAL PROGRAMMING

DCHD can identify where eligibility is a barrier to needed services and support and identify policies or approaches to ensure that these resources are more universal or open to all.

Introduction

The Douglas County Health Department (DCHD) engaged Health Management Associates, Inc. (HMA), a national research and consulting firm with an office in Colorado to conduct a community landscape scan focused on existing resources and resource gaps for Children and Youth with Special Health Care Needs (CYSHCNs) and their families. This assessment explored the barriers and facilitators to accessing community resources for Douglas County CYSHCNs and their families.



The assessment findings will be used by the DCHD to inform strategies to pursue in achievement of its goal that all children, youth, and families in Douglas County are valued, healthy and thriving.

Methodologies

Four approaches were used to inform the landscape scan:

- 1. Community provider key informant groups
- 2. Caregiver of CYSHCNs focus groups
- 3. Caregiver of CYSHCNs survey
- 4. Community meeting

Community Provider Key Informant Groups

As part of the needs assessment, HMA conducted interviews with key informant stakeholders (KIIs) identified by the DCHD. The purpose of these interviews was to gather information from the perspective of key leaders and understand the ongoing efforts in Douglas County to enhance outcomes related to the health, development, and well-being of CYSHCNs. Four key informant group interviews were conducted, representing different perspectives:

- School-based perspective: Three participants.
- County perspective: Three participants.
- Community-based organizations/service provider perspective: Six participants.
- Individuals with Developmental Disabilities (IDD) service provider and parks and recreation programs: Nine participants.

Each interview lasted approximately 90 minutes and involved one HMA facilitator and one HMA note taker. The discussions were recorded to aid in recall and clarification. A facilitation guide was utilized to structure the group interviews and ensure consistency across the KII groups. The guide was shared with the participants 24 hours prior to the discussions. Appendix A is the community provider key informant group guide.

Caregiver Focus Groups

In addition to the key informant interviews, HMA conducted four focus groups with 26 caregivers between April 26th and May 5th, 2023. DCHD also conducted two additional focus groups between May 9th and 10th, 2023, with 20 participants. Figure 1 shows the number of participants by ZIP code, revealing representation across the county.. The focus groups aimed to represent a diverse group of Douglas County families, considering the age of the child or youth represented among the caregivers and their specific health care needs. The average age of the child being cared for among the focus group participants was 8.7 years, ranging from 5 years old to 16 years old. Disclosed health care needs included Autism, Down Syndrome, asthma, intellectual disability, attention deficit hyperactivity disorder (ADHD), and physical disability. Social media was the predominant way caregivers learned about focus group opportunities, specifically, Facebook. Appendix B is the caregiver focus group guide.



Figure 1 Number of Caregiver Focus Group Participants and Survey Respondents by Zip Code

of Caregivers



Caregiver Survey

There was a significant interest from caregivers to participate in the focus groups, with 298 caregivers responding to a Doodle Poll identifying the dates and times they could join a discussion. Due to time and budgetary limitations to engage all caregivers, a survey was developed and shared with all interested caregivers who were not selected to join the focus groups. The survey was also publicized during the community meeting. The survey reflects similar questions to those asked in the caregiver focus groups. It was designed and administered using Google Forms. Fourteen caregivers submitted a response to the survey.

HMA then prepared and presented findings and recommendations from the above to report to the DCHD Community Health team and stakeholders who participated in the assessment. Appendix C is the caregiver survey.

Community Meeting

A community meeting was held May 18, 2023 from 7:30-9:30 am. All caregivers, key informants, and additional community providers were invited to attend.

The agenda for the meeting included presenting on the purpose and goals of the landscape scan, sharing preliminary findings from the interviews and caregiver focus groups, and a facilitated discussion among participants. The discussion questions included:

- 1. Is there anything additional you would share that you feel is not captured?
- 2. Within these key findings, what should be a priority?
- 3. What are the additional opportunities for Douglas County Health Department?
 - If you could choose one intervention for that priority area, what would it be and why?
 - What are the barriers to offering these interventions in Douglas County?
- 4. Who are the partners public health needs to have?

Appendix D are the community meeting slides. There were 58 registrants for the meeting, among which included 42 caregivers of CYSHCNs. Organizations represented included:

- Advocates for Children CASA CMP
- AllHealth Network (3)
- ARC of Colorado
- Blessed Love Behavior Services
- Developmental Pathways (2)
- Douglas County (8)
- Early Childhood Mental Health Consultation
- Early Childhood Parent Resources

- Highlands Ranch Community Association (HRCA)
- My Gym Highlands Ranch
- Open Heart Behavior Services
- Parent to Parent of Colorado (2)
- The ARC of Arapahoe Douglas and Elbert
- THINK-12 Organization

A Snapshot of CYSHCNs in Colorado and Douglas County

CYSHCNs are defined as children from birth to age 21 who have or are at an increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

Families caring for CYSHCNs find themselves navigating various complex systems such as healthcare, insurance, behavioral health services, and school systems that are rarely coordinated. Often, navigating these systems is a convoluted and burdensome process to obtain even the minimum care needed for their child.

According to the 2016-2017 National Survey of Children's Health (NSCH), nearly one in five (18%) of Colorado's children and youth, age 0-17 years, had a special health care need, similar to the prevalence of CYSHCNs nationwide (19%). This translates to approximately 341,000 CYSHCNs ages 0-25 years in Colorado. According to the Colorado Department of Public Health and Environment (CDPHE), there are 24,837 CYSHCNs ages 0-25 years living in Douglas County.

Special Education Enrollment

The percent of students enrolled in special education programs in Douglas County School District is comparable to other school districts in Colorado. Special education enrollment is on a small increasing trend in both Douglas County and Colorado, from approximately 11% of students in 2018 to 12% of students in 2021. In Douglas County, this is an average of 7,500 students enrolled in Douglas County per year.¹

Conditions among CYSHCNs

The majority of Colorado CYSHCNs (64%) had two or more health conditions, and one in four (27%) had one health condition. The top five most reported health conditions among CYSHCNs were allergies, ADHD, learning disability, anxiety, and asthma, as shown in Figure 2.

¹ State of Colorado Special Education Data



Figure 2 Common Health Conditions Among CYSHCNs in Colorado, 2016-2017

Source: State of Colorado Special Education Data

As shown in Figure 3, the most prevalent disability among CYSHCNs ages 5 to 21 years in Colorado are learning disabilities (42%) followed by speech or language impairment (14%) or other health impairment (13%). Autism occurs among one in 10 children with a disability (9%).





Source: Colorado Department of Education, Colorado IDEA Child County

Douglas County Community Context

Social determinants of health (SDOH) are the social, economic, and environmental factors that influence an individual's health outcomes. They play a crucial role in shaping the well-being of CYSHCNs and their families. Economic stability and spoken language were two important factors noted in the caregiver and KII groups.

Economic Stability

SDOH, such as poverty, unemployment, and housing instability, can significantly affect the lives of families with CYSHCNs. Financial difficulties can limit their ability to afford necessary medications,

adaptive equipment, and home modifications. Inadequate housing conditions or frequent relocations can lead to increased stress, disrupt routine care, and negatively impact the child's health outcomes.

The Hardship Index is a composite score reflecting hardship in the community (higher values indicate greater hardship) and is reflected in Figure 4.² Colorado had a score of 34.8, significantly higher than Douglas County at 9.6. Douglas County communities range from a low score of 2.4 (Perry Park, 80118) to 29.4 (Woodland Park, 80863). Communities higher than Douglas County average were ZIP codes located in Parker (80138, 80134), Franktown (80116), Roxborough Park (80135), Parker (80138), and Castle Rock (80104, 80109).



Figure 4 Hardship Index by ZIP Code

Source: Urban Institute Methodology, American Community Survey, 2017-2021.

² The Hardship Index is a composite score reflecting hardship in the community (higher values indicate greater hardship). It incorporates unemployment, age dependency, education, per capita income, crowded housing, and poverty into a single score that allows comparison between geographies. It is highly correlated with other measures of economic hardship, such as labor force statistics, and with poor health outcomes.

Language

The language barrier can present significant challenges in accessing care for CYSHCNs. Language barriers can impede effective communication between healthcare providers and families. This can lead to misunderstandings, incomplete medical histories, and challenges in explaining symptoms or understanding diagnoses and treatment plans.

Families may also struggle to access and understand essential information about available healthcare services, specialists, support programs, and community resources due to language barriers. This lack of information can hinder their ability to make informed decisions regarding their child's care.

Language barriers may result in the misinterpretation of symptoms or concerns, leading to incorrect diagnoses or delayed treatment. This can adversely affect the child's health outcomes and potentially lead to complications. Children from diverse cultural backgrounds may have unique healthcare needs and beliefs. Healthcare providers who are not familiar with their culture or language may struggle to provide culturally sensitive care, leading to suboptimal outcomes or reluctance to seek care.

Nearly 5% of households in Douglas County have Spanish as the primary language in 2017-2021. This is compared to 11% of households in Colorado. Communities with a high percent of households who speak primarily Spanish are Meridian (8.1%), Larkspur (7.7%), Lone Tree (7.2%), Castle Rock (6.6%), The Pinery (5.2%), and Parker (5.0%).

Health Care System for CYSHCNs

In Colorado, in 2020-21, approximately one in 10 (12.2%) CYSHCNs met the criteria for receiving care within a well-functioning system (criteria include: family-clinician partnership, medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition). This was a decrease from one in five (17%) in 2016-2017. Access to specialty care, receiving care within a medical home, and successful transition from pediatric to adult care contribute to a well-functioning health care system for CYSHCNs.

Receiving care in a well-functioning system is, in part, determined by the age and race/ethnicity of the child. As shown in Figure 5, older youth (12-17 years) are less likely to receive care in a well-functioning system (4.3%) compared to children 0-5 years at 14.7% and 6-11 years at 21.2%. Hispanic (10.5%) or non-white youth (7.9%) are less likely to receive care in a well-functioning system.



Figure 5 Percent of CYSHCNs Who Receive Care in a Well-functioning System in Colorado, 2020-2021

Source: The National Children's Health Survey, 2020-2021. National Outcome Measure.

According to the 2021 Colorado Health Access Survey (CHAS), one in five (20.1%) of Douglas County residents have public health insurance (Medicaid/CHP+ or Medicaid).³ NCHS suggests that CYSHCNs using only public health insurance have significantly lower access to a medical home that meets criteria. The NCHS uses five components to assess whether a child/youth meets the criteria for having a medical home: (1) have a personal doctor or nurse, (2) have a usual source of sick care, (3) receive family centered care, (4) have no problems getting needed referrals and (5) receive effective care coordination when needed.

In Colorado, as shown in Figure 6, 39.3% of CYSHCNs on public insurance who have a medical home with care that meets criteria compared to 46.8% with private health insurance or 54.0% with a combination of private and public health insurance.

³ Colorado Health Access Survey, 2020-2021.



Figure 6 Percent of CYSHCNs, Ages 0 through 17, Who Have a Medical Home with Care That Meets Criteria, Colorado, 2020-2021

Source: The National Children's Health Survey, 2020-2021. National Outcome Measure 17.2

Access to Specialty Care

According to the CHAS 2020-2021 survey, 14% of Douglas County residents were unable to get an appointment with the doctor's office/clinic as soon as they thought one was needed (compared to 18.6% for other Coloradans). Obtaining appointments with specialty care was significantly more challenging in Douglas County. Nearly half (43.8%) of Douglas County residents were unable to get an appointment with specialty care compared to nearly three in 10 (27.5%) of other Coloradans (Figure 7).

Figure 7 Unable To Get An Appointment With The Doctor's Office/Clinic As Soon As You Thought One Was Needed, By Type Of Care



Source: Colorado Health Access Survey, 2020-2021

Summary of Community Provider and Caregiver Focus Group Findings

The following summary presents findings from the four data collection methods, and is organized by the undermentioned topics or themes:

- What is Working Well in Douglas County
- Priority Areas for CYSHCNs
- What is Not Working Well in Douglas County
 - o Access to Care Barriers
 - Gaps in Caregiver Supports
 - o Gaps in Resources
- Major Health, Development, and Well-being Issues for CYSHCNs and their Caregivers
- Influence Factors of Health Care Coverage
- Community Collaboration

It is important to note that the information shared by the caregivers during the focus groups showed that there is no one "typical" caregiver and no one "typical" caregiver experience. Needs and expectations vary and can be constantly in flux.

What is Working Well in Douglas County

These themes highlight the strengths and successes in Douglas County's efforts to support children with special health care needs. The commitment to inclusive education, the availability of community resources, the creation of inclusive parks and recreation programs, and the provision of comprehensive support systems collectively contribute to the well-being, development, and overall success of children with special health care needs in the county.

Caregiver perspective: There was a sense that when families are connected to services, it is a positive experience. Caregivers expressed satisfaction with the medical services provided for their children and the support they receive from schools and communities. They also highlighted the effectiveness of various programs and mental health services in meeting the needs of children with special needs. The support of family and friends has been a significant factor in their success, with some reporting their children are doing better in school and making friends. The proximity of medical facilities has also been helpful for accessing.

Inclusive Education

Schools in Douglas County have made significant strides in implementing inclusive policies and practices that prioritize the educational success of CYSHCNs. The school district has dedicated resources and staff to provide individualized education plans and support services tailored to the unique needs of students with disabilities. This commitment to inclusivity is exemplified through partnerships with hospitals, such as the implementation of Sources of Strength, which fosters a supportive and inclusive environment within schools. Additionally, schools have prioritized

professional development initiatives focused on trauma-informed practices and approaches, as well as restorative practices, ensuring that students with special health care needs receive the necessary support for their overall well-being and educational development.

Quote(s):

- "I did not have many challenges because my son's school staff were very supportive and patient. Without them, I would have had to have him stay at home, which would have been challenging for me in my work."- Douglas County Caregiver
- "My son is doing way better in school now and making more friends...this is such a big success because I remember praying for times like this." Douglas County Caregiver

Abundance of Community Resources

Douglas County boasts a rich array of community resources and organizations that actively provide support and services to CYSHCNs and their families. The Developmental Pathways agency, the ARC of Colorado, the Special Olympics, and the presence of the Children's Hospital Colorado clinic in Highlands Ranch are just a few examples of the diverse range of resources available. These organizations play a crucial role in connecting families with essential services. They provide assistance, guidance, and opportunities for CYSHCNs to thrive in various aspects of their lives. The collaborative efforts between these community resources and families contribute to the overall wellbeing and development of the children and youth.

Quote(s):

• "The story of success about my child and my family is that most of the time my child has been accepted by many people, despite his conditions, and a lot of people show us love here in the community." - Douglas County Caregiver

Positive Experiences and Support

Caregivers expressed satisfaction with the services provided for their CYSHCNs and the support they receive from various stakeholders. Medical services were highly regarded, with caregivers appreciating the accessibility and quality of care available to their children. Furthermore, the support and patience demonstrated by school staff were cited as instrumental in facilitating their children's educational journeys. Programs such as the Supplemental Nutrition Assistance Program (SNAP) program were mentioned as invaluable resources within schools. Caregivers also emphasized the significance of the support they received from family and friends, which played a pivotal role in their child's success and well-being. These positive experiences and support systems contribute to the overall positive outcomes and improved quality of life for CYSHCNs in Douglas County.

Quote(s):

- "Physical therapy services are really encouraging, and we find some hope in it that our child will have a normal life someday." Douglas County Caregiver
- "We have also been able to access a medical facility in the hospitals whenever we require them."
 Douglas County Caregiver

• "[The] SNAP program has been very helpful, you know, in the child schools as well." - Douglas County Caregiver

Inclusive Parks and Recreation

Douglas County has created inclusive parks and recreation programs that are accessible and welcoming to CYSHCNs. The county has built several playgrounds and facilities that are designed to accommodate children with disabilities.

Priority Areas for CYSHCNs

There are seven priority areas defined by CDPHE Maternal and Child Health (MCH) Advisory team in their 2021-2025 Title V Block Grant cycle. KIIs and caregivers (in part through the survey and focus group discussions) were asked to share what would be their top three priorities for DCHD to work on over the next five years when thinking of CYSHCNs and their families. As shown in Figure 8, overall, "improve access to support" was the top priority selected by both community providers and caregivers, followed by "increase social emotional well-being". "Creating safe and connected built environments and "promote positive youth development" were both a third priority.

Figure 8 CDPHE Maternal and Child Health Framework: Prioritization for CYCHSNs Among Community Provider Key Informants and Caregivers of CYSHCNs



Note: Results represent the community provider participant poll results (n=21), and the combination of caregiver focus group participants through qualitative statements (n=16) and the caregiver survey (n=14). Results should be interpretation with caution due to the different data collection methods.

51% Improve access to supports

45%

43% Create safe and connected built environments Promote positive youth development

39% Reduce racial inequalities

27% Increase prosocial connection

20% Increase economic mobility

Improve Access to Supports

Increase meaningful access to supports for MCH and families

KIIs emphasized the need to improve access to care and support for CYSHCNs and their families. KIIs shared their perspective on what it was like for families trying to access care and support. The word most used was "frustrating". As one school professional stated "it's affordability, its coverage, but also just workforce, like having a clinician. It's like trifecta issues." They highlighted various barriers, including limited access to specialty care, challenges in care coordination, lack of awareness about available services and supports, transportation barriers, and language and cultural barriers. Since this was a priority area for both caregivers and community providers, the barriers in access and opportunity to improve access to support are described in more detail in the next section: *What is not working well: Access to Care Barriers*.

Increase Social and Emotional Well-being

Families across the lifespan have support systems and supportive environments that allow them to thrive.

Caregivers and KIIs expressed a need to prioritize social and emotional well-being, suggesting a focus on mental health, emotional resilience, and social connectedness. Increasing social and emotional well-being is a key element of providing comprehensive care. KIIs spoke to the "ripple effect" of not addressing social and emotional well-being on health and educational outcomes, quality of life, and mental health. School and provider referrals were also reported to increasingly focus on mental health needs and services when reflecting on the last several years. Caregivers spoke to a sense of isolation their child feels, and the impact it has on their social and emotional well-being. Suggestions included implementing programs promoting mental health awareness, emotional regulation, social skills training, peer support groups, and activities enhancing self-esteem and confidence.

Quote(s):

- "Support group for the kid and help them see themselves as "one of us". Mental health, people think mental health is just for adults, but it's for kids too, and [it is important] to have someone to talk to other than parent. It was hard for me when my child was having issues expressing herself. Help bring the kids together with this disorder, someone who is the same as them, would feel more connected and won't be alone, togetherness." -Douglas County Caregiver
- "Need to "helping [children] feel normal and not left out, please accept them for who they are, inclusion, give them joy and happiness." -Douglas County Caregiver
- "We need to put the emotional well-being of our children first while trying to create a safe space and safe environment for our children and their future. We should also make sure that their emotional well-being is being treated with full or 100% care because there are a lot of issues children are going through some issues and it should be a priority to address these. -Douglas County Caregiver

Create Safe and Connected Built Environments

All Coloradans will have increased access to safe places to walk, bicycle, wheelchair roll, and to create community connections.

Promoting Positive Child and Youth Development

All Colorado children and youth have developmentally appropriate and culturally responsive relationships and have access to the environments and opportunities they need to thrive physically and emotionally.

These two priority areas were discussed interchangeably. More environments are needed that are inclusive and welcoming, for both the caregiver and CYSHCNs. These environments are particularly important for CYSHCNs from a healthcare/medical perspective, accessibility perspective, and inclusion perspective. CYSHCNs may have physical and mobility challenges that require accommodation in the built environment, such as wheelchair accessibility, handrails, and other safety features. Creating safe and accessible environments can reduce the risk of accidents and injuries. Safe and accessible parks, playgrounds, and recreational facilities can promote physical activity and overall health and well-being. Creating built environments that are accessible and easy to navigate will promote independence and self-reliance and can help promote a sense of belonging as well as support social interaction and participation.

Quote(s)

- "...Also, the best thing for me is to create an environment where they believe it is OK for me to be myself." Douglas County Caregiver
- "…Create safe and connected built environment. Why- because it's essential to our daily living. And promote positive child and youth development and increase social and emotional wellbeing. I support the two because they would create opportunities for youths and help to enhance mental health." – Douglas County Caregiver
- "We need positive child development because we are working for and trying to lead people towards their goals." Douglas County Caregiver

Increase Prosocial Connection

All people can form and maintain healthy individual, family and community-based relationships, throughout life, no matter where they live, learn, work, play or pray.

KIIs expressed a desire to foster prosocial connections among CYSHCNs, staff, and the community. Prosocial connections can positively impact social and emotional well-being, reduce risk behaviors, and enhance academic success. Greater community engagement opportunities, collaborative programs, and inclusive built environments were seen as means to promote positive social interaction and belongingness. Caregivers often connected increased prosocial connection to their child's social and emotional well-being. As stated previously, caregivers spoke to the isolation their child feels, and the need for inclusion or opportunities to connect with other CYSHCNs.

- "... need safe environment for LGBTQIA community. People feel like they are not part of society and have been discriminated against by other people. We need to show that there is a safe space for everyone." Douglas County Caregiver
- "I'd like to say something on the recreational activity. For me, personally, there are activities organized for kids. Sometimes I feel that my own child doesn't fit in because of a disability sometimes she feels like so left out, you know she doesn't really get to play like all the kids, you know." -Douglas County Caregiver

Reduce Racial Inequalities

Reduce racial inequities in Colorado through policy and systems changes to the MCH program, division and/or department.

It was acknowledged that race and ethnicity disparities exist in Douglas County, and that a child or family's demographics, such as race/ethnicity, economic status, and/or language spoken can mean they do not have the same system of care or access to supports. A KII stated that "resources are not the same for Black or Hispanic families. When resources are available, it may not be a culturally appropriate resource and/or it's delivered with bias and stigma and may lack cultural awareness." Several KIIs also noted the lack of cultural competency in both the services and providers delivering the services.

Caregivers reported feeling discriminated against in terms of their access to supports for their CYSHCNs. They mentioned delays in care due to discrimination based on race/ethnicity and feeling like they are not receiving enough support. Discrimination was identified many times as a barrier to accessing necessary resources and support.

Quote(s):

- "My child is black and assessing health is sometimes hard because of situation or the quality [of that care]. I feel bad because [my child is] being deprived of healthcare that he is supposed to get for free. Hard finding services that are low cost." -Douglas County Caregiver
- "I have been given attention in time and clinicians also provide any further information I might need from them; What does not work well is that sometimes there are delays and discrimination based on ethnicity."- Douglas County Caregiver
- "I believe if racial inequalities are reduced a lot of people will have access to support". Douglas County Caregiver
- "My husband is white and I am Black, but when going to a doctor's office alone I was treated differently and my husband was treated a different way. Since we are married we talk about our experiences, it is something totally different."- Douglas County Caregiver
- "Difficult and discriminating. I find it difficult and very annoying to have access to the services and the medical personnel are discriminating and not open to diverse culture."- Douglas County Caregiver

Increase Economic Mobility

Increase economic mobility for Colorado families by addressing racial inequities and disparities in policies, practices, and systems.

KIIs shared that affordability of the services and supports was a barrier for families with CYSHCNs, who often require specialized medical care and support services, which can be expensive. Economic mobility can help families access the healthcare their children need. CYSHCNs require accessible and safe housing and transportation options, which can be more expensive. Economic mobility can help families afford these necessities.

Quote(s):

• "The next is economic stability because we all need money and the global economic return about money and how we cannot afford things."- Douglas County Caregiver

The extent to which these priorities shifted for KIIs in consideration of a special age group was small. Generally, KIIs felt that the priorities they selected applied to all age groups, with some exceptions.

- For children, 0-5 years, priorities shift towards access to supports, and specifically affordable and quality childcare, and offering prosocial supports for the caregiver.
- For young adults 18-24 years, the priority shifted for some to creating safe and connected built environments and primarily with a focus on safe housing.

What is Not Working Well in Douglas County

Findings from the community provider discussions, caregiver focus group and survey, and community meeting about what is not working well in Douglas County for CYSHCNs and their caregivers is described in three parts: Access to Care Barriers; Gaps in Caregiver Support, and Gaps in Resources.

Access to Barriers

KIIs emphasized the need to improve access to care and support for CYSHCNs and their families. KIIs shared their perspective on what it was like for families trying to access care and support. The word most used was "frustrating". As one school professional stated "it's affordability, its coverage, but also just workforce, like having a clinician. It's like trifecta issues." They highlighted various barriers, including limited access to specialty care, challenges in care coordination, lack of awareness about available services and supports, transportation barriers, and language and cultural barriers. To address these issues, creating clear pathways to access support services, enhancing education and training opportunities on resource navigation, and improving communication between families and service organizations are essential.

Quote(s):

- "Can be a full-time job to figure out access. And I have been lucky to have the time to do it." Douglas County Caregiver
- "Very difficult to get access to medical support and transportation. It is very frustrating. Public transportation is limited as well. It is a big barrier. I use public transportation because I do not have a vehicle, so it's kind of like a barrier for me to access her medical support." Douglas County Caregiver

The caregiver survey indicated that the top barriers to care were:

- My child(ren) was not eligible for services (57%, n=8)
- I could not find providers or services that understand, value, and respect my culture (43%, n=6)
- I did not know what services and resources were available (43%, n=6)
- Forms were too complicated (Medicaid, Health Insurance, or doctor's office/hospital forms etc.) (43%, n=6)
- High out-of-pocket-costs/it costs too much money (43%, n=6)
- No appointments were available, or I couldn't get an appointment in a reasonable amount of time (36%, n=5)

A summary of access barriers described by KIIs and caregivers include:

- *Limited Access to Specialty Care:* While Douglas County has a range of healthcare providers and community-based resources, access to specialized services for CYSHCNs is limited, particularly in rural areas of the county. Some examples of poor access shared were an anecdote of eight weeks to see a pediatric neurologist or one parent who noted that they would have to wait four to six weeks for their child to see a mental health provider.
- *Barriers to Care Coordination:* Navigating the healthcare system and coordinating care across multiple healthcare providers and community-based resources can be challenging for families, particularly if they are not familiar with available resources.
- Awareness of Services and Supports Available: Knowing whether resources exist and how to access them was another access barrier shared across the KII groups. It was noted that resources are changing all the time and no one system is monitoring and creating a directory. Supports noted to be of particular importance and challenging to access for CYSHCNs were mental health services, counseling, special education services, and other resources that promote well-being. What KII participants noted was a need for creating clear and accessible pathways to access support services, which should include education and training opportunities on how to navigate available resources. These pathways should be accessible and known to both families and the child, youth and family serving organizations. One KII shared "I was amazed at how many programs we have in Douglas County, but I don't think they're well-advertised. And I don't think our families know that they exist."

- *Transportation Barriers:* Transportation can be a significant barrier for families seeking access to healthcare services and support resources, particularly if they live in rural areas of the county. Children in rural or remote areas may face greater challenges in accessing care, as there may be fewer providers available or longer distances to travel to access care. As one of the school professionals stated: "if someone wants to go in person, that's all the way in Littleton. If one of my families is in more rural Parker and they don't have a car, it is more difficult to access care."
- Language and Cultural Barriers: Children and families from diverse cultural and linguistic backgrounds may face challenges in accessing care due to language and cultural barriers.

Caregivers emphasized that affordability of services and support was a barrier. The affordability of services and support was a major challenge that was discussed in all focus groups. Many individuals are unable to access the care due to high healthcare costs, lack of insurance coverage, or inadequate financial assistance. These challenges can be particularly difficult for low-income individuals or those who are underinsured or uninsured.

Quote(s):

- "I have a 5-year-old, with down syndrome, and it's been very high cost accessing healthcare."
- "I believe if everyone could access health with a limited low cost it will be of help."
- "My insurance does not cover all the costs and it makes it difficult to pay for our hospital bills because of the low income."
- "[In regard to difficulties they face] The cost for medication."
- "[We face] several challenges with accessing healthcare like high cost."

Access to basic needs such as transportation, housing, and food was discussed as a major barrier to accessing healthcare among Caregivers. Not having these things makes it difficult to attend medical appointments and access medical services.

Quote(s):

- "I have a problem with the location of my healthcare facilities. I will have to spend a few bucks on transportation."
- "Our transportation issue, you know, I'm trying to get my child to school and trying to get to the office."
- "Challenges around transportation and the support that you look for in your community to get you through the days."
- "[In regard to where needs are not being met] Proper health insurance, food, housing."



• "[In ZOOM chat regarding where they need assistance] Housing.

Gaps in Caregiver Support

Caregivers were provided the following list of supports, and asked to share where they would want or need more support. While all were referenced at some point by caregivers, the first three (top row, Figure 9) were predominantly noted as the areas where more support was needed. Caregivers in Douglas County are facing challenges in accessing specialized medical practitioners, obtaining the right information and resources, and accessing services for their children.

Figure 9 Caregiver Supports

Finding local services and supports	Understanding a child's medical and behavioral health care needs	Accessing care and schedule appointments with providers
Coordinating communication across their child's health care team	Connecting to others who can address food, housing, and transportation needs	Planning and preparing for life transitions

Finding local services and supports. Caregivers often must navigate complex systems and bureaucracies, which can be overwhelming and confusing. Many caregivers report feeling frustrated by the amount of time and effort required to find the right supports, as well as a sense of confusion about where to begin. One of the primary reasons for this frustration is a lack of complete information about the services and supports that are available. Caregivers may be unaware of the full range of resources that are available to them, or they may not know how to access those resources. This lack of information can be particularly challenging for caregivers who are newly learning about their child's special need(s). Lastly, many parents struggle to find the right practitioner or specialist due to cost and transportation concerns.

Quote(s):

• "You just have to go around. Look for it. And it's difficult. Maybe the services are there, but it's difficult to know if they're there, and maybe even to find them." – Douglas County Caregiver

- "[Access to non-medical/health supports and services] It's way much easier now. It was so much of a big deal at first but things feel easier now." -Douglas County Caregiver
- "Everything was taking a long time to do all the leg work on my own." -Douglas County Caregiver

Accessing care and schedule appointments with providers. Access to specialty care can be extremely challenging for many individuals. In many cases, there simply are not enough specialty care providers available to meet the needs of patients. Getting both a referral and the appointment can be a significant challenge. They also face delays in accessing appropriate care due to a lack of information and resources.

Quote(s):

- "[You] can't just book an appointment...You just have to verify, then it's also taking time for the doctors to refer to the special list". Douglas County Caregiver
- "I feel like my issue is scheduling appointments...They could extend the working hours, or maybe during the weekend, even if it's just maybe till the afternoon."
- "Booking appointment is my main challenge." Douglas County Caregiver
- "[I need support] finding providers, getting all the information and paperwork ready that is needed for appts. I have had difficulty going through the papers before. Getting access to a provider as well." – Douglas County Caregiver

Understanding a child's medical and behavioral health care needs. Caregivers emphasized the importance of understanding a child's medical and behavioral healthcare needs, finding local services and supports, and creating a welcoming environment for children. They expressed the need for resources and support to help them navigate the healthcare system, communicate effectively with healthcare providers, and better understand their child's needs.

Quote(s):

 "I find it difficult to understand my child's behavior and don't know what to do in terms of emergency health care. Am always delicate when it comes to him because he is autistic. I think I need a manual on that aspect." – Douglas County Caregiver

Gaps in Resources

Caregivers were provided a list of resources and asked to share which of the list would they consider the top three source that they wish there was more of in Douglas County:

- Residential
- Home and community- based supports
- Adult day
- Non-emergency transportation
- Dental
- Medical
- Mental health
- Crisis/emergency supports
- In-home respite
- Out-of-home respite (temporary support)
- Educational services

- Clinical services (occupational therapy, physical therapy, speech/language therapy)
- Vision services
- Durable medical equipment
- Home modifications
- Early intervention (services for students 0-3 years)
- Pre-school special education (services for students 3-5 years)
- Infant services
- Recreational activities
- Other therapies (music, recreation)

Among the options, mental health, early intervention, and education services were commonly selected. Other resources that were chosen less frequently included non-emergency transportation, in-home respite, and recreational activities. The caregivers identified several reasons why they wished certain resources were more available in Douglas County which included the following:

- Some resources were already available and working well, but there simply was not enough of them to meet the demand.
- Lack of access was a significant barrier for some caregivers, as some resources were too expensive or they lacked eligibility due to certain restrictions or requirements.

Early intervention – Access to that first or early diagnosis was challenging. Caregivers describe first not knowing or understanding a child(s) behavior or symptoms and finding it difficult to understand what it is their child needed. There were challenges expressed during the diagnosis process. For example, a family doctor was unable to diagnose and then it was difficult to find a specialist who could. During these times, caregivers express a need for someone to help them through the process and know what was going on.

Quote(s):

- "At first really challenging, didn't know where to start, heard from a friend/family where to start, not knowing where I could get the support was really difficult." Douglas County Caregiver
- "Clinical services (occupational therapy, physical therapy, speech/language therapy), educational services, preschool special education. Why- to me I believe we all need those three key things to support us. Why- it is available but not enough and we have a large number of children here in Douglas County." - Douglas County Caregiver

Mental health care for children is not accessible for many. Caregivers expressed concern over the lack of accessibility to mental health care for children. They highlighted the need for professional help and support for kids struggling with mental health issues, such as psychiatrists and counseling services. The caregivers emphasized the importance of having more resources and connections to improve the mental health of children in Douglas County.

Quote(s):

- "And I also talk about mental health accessing. The services like a psychiatrist who can deal with the kid and tell them this is normally they are not left alone." Douglas County Caregiver
- "Mental health care, support, and medical supports not really accessible." Douglas County Caregiver
- "So, all these kids [may have challenges with] mental health, I think sometimes we need to talk to a professional." Douglas County Caregiver
- "I need more connection. It could improve their mental health. And you know, in general, I think that's something I want an improvement on." Douglas County Caregiver

Need for educational services. Caregivers expressed concerns about the education services available for children with disabilities, stating that educational services should be improved and increased. They believe that the government should provide social amenities and quality education to children with disabilities. As one caregiver states "we need schools with other students like them." Additionally, they emphasized the need for early-stage education support for children with disabilities.

Quote(s):

- "I think that educational services should be improved, or maybe increase. I want the education services where my kid will be comfortable getting what he needs." - Douglas County Caregiver
- "[Need for] Education support for children of disability at early stage of life." -Douglas County Caregiver
- "There should be a school for autism. There needs to be teachers and safe who are proficient and language needs to be a focus. Students with autism should learn to communicate with sign language and school staff should learn as well. We want a better future, and inclusive communication for students with autism." -Douglas County Co



communication for students with autism." -Douglas County Caregiver

Resource Utilization and Needs

The caregiver survey asked respondents to select the resources they currently use and what types of resources does your family need to access but have not yet, as shown in Figure 10. While this represents 14 caregiver perspectives, it does align with the identified needs and resource gaps. For example, "social and emotional support" is something that 36% of the caregiver survey respondents

indicated as needed but have not accessed, followed by specialty services for people with disabilities (21% or one in five caregivers). Job placement and training, while not a theme that was elevated during the caregiver focus groups, it is important to note that the survey responses reflect the experience of three families with a young person with special health care needs age 18-24 years. Health insurance, education, and child-care were resource gaps that aligned with themes from the caregiver focus groups. Caregivers indicated that resources used are health and mental health care, childcare, and case management or resource navigation. utility assistance, veterans programs, transportation options for teens who can't drive due to disabilities, senior programs and services, legal assistance, LGBTQ+ support group, respite, and housing assistance were resources caregivers were least likely to report using and/or needing but have not yet.

Figure 10 Access to Resources and Need for the Resources



Building Awareness of Services and Supports for CYSHCNs

Caregivers were asked to share how they learned about resources available to them, either as a caregiver of a CYSHCNs or for other needs in your life.

Caregivers expressed a reliance on community members as sources of trusted information. Advice and recommendations from friends and family members, as well as other professionals they know, can provide assurance of the quality of the services or supports that can meet the needs of their care recipients. They often rely on advice and recommendations from people they trust, as well as other professionals they know, to help them navigate the complex systems of services and supports for their care recipients. This is because they feel that the information they receive from these sources is more likely to be accurate and trustworthy.

Caregivers recommended that sharing quality information in a variety of ways could boost overall awareness of the resources that are available and reach a range of caregivers. They suggested using various communication methods, such as social media platforms, brochures, flyers, postcards, and information packets from medical professionals, as well as advertising in print media. By utilizing multiple avenues to share information, caregivers felt that the resources could be more widely distributed and accessible to people who might not have easy access to online resources or those who prefer to receive information in a more traditional format.

Building awareness is essential for ensuring that these children receive the care they need. Leveraging the trusted places and people families turn to for helping to build awareness is an important first step. These places and people include:

- *Healthcare Providers:* Providers can educate families about available services, provide referrals to specialists and other providers, and coordinate care across different settings. For this to work in Douglas County, KIIs shared that a concerted effort to educate and inform providers of the opportunities for CYSHCNs is needed. However, caution is needed to ensure that the role of a healthcare provider is protected, and that within the health care setting there needs to be resources and staff who can implement this awareness building.
- *Schools:* Schools can provide education and support for children with disabilities and other special needs, and work with families to develop individualized education plans (IEPs) to meet their needs. In Douglas County, KIIs shared that the extent to which screenings, assessments and other individualized supports are available for CYSHCNs can vary by school setting. There is an opportunity for best practice standardization across schools.
- *Community Organizations:* Community organizations, such as parent support groups, disability advocacy organizations, and local nonprofits, can also provide information and resources to families of CYSHCNs. Examples of CBO assets were shared, such as Parent Café that seek to include and engage families in meaningful conversations about their experiences and needs and create space for social connection.

• Social Media and Online Resources: Social media and online resources can also be valuable tools for increasing awareness of services and supports for CYSHCNs. Online forums and support groups can provide a sense of community for families, while websites and online portals can provide information about available services and supports. One caregiver said "One of the best resources that I am a part of is a Facebook group that feels localized and meeting people with more people in real time. Douglas County is so large, but even localizing and creating community within the large county." While this works for many, there needs to be alternatives for families who find accessing online supports complex and overwhelming and are not trusted in the same way a family, friend, or health care provider may be.

Specific interventions that were suggested include:

Advertisement/Resource Center: Creation of a common space for families, providers, and the community to access these resources (i.e., newsletters and a website with resources). A website with links to resources and public service ads promoting available services could be a valuable intervention to improve the health and well-being of CYSHCNs. Many families may not be aware of the resources and services available to them, and a centralized website could make it easier for them to access this information. One KII representing a CBO referred to this as a "community of care" and used the example of the Douglas County Department of Human Services (DHS), which was described as a user-friendly website that is known throughout the community and includes links to services. The KII went on to describe: "It's like they go to one place, they find what they need and we're all there, you know, with our smiling faces ready to help."

Public Service Announcements: Additionally, public education campaigns and community partnerships could help to increase awareness of available services and improve coordination between providers and organizations.

Family Advocate: KIIs mentioned the need for a liaison or advocate who can help individuals navigate the process of accessing Medicaid/Medicare services, particularly for those with CYSHCNs. This may involve assistance with understanding eligibility requirements, finding providers, scheduling appointments, coordinating transportation, and addressing other challenges related to accessing Medicaid/Medicare services.

Wrap Around programs: Wraparound programs are community-based services and support programs that aim to help children and youth with complex needs and their families succeed in their homes and communities. These kinds of programs do exist in Douglas County, and there is an opportunity to leverage lessons learned. For example, Douglas County Mental Health Initiative (DCMHI) is expanding its program to offer not only crisis intervention support but also wrap around programming. It is important to ensure that these programs are well-advertised and accessible to all families in need.

Community Collaboration

Collaborative efforts among healthcare providers, Medicaid/Medicare agencies, transportation agencies, schools, and community organizations may be needed to overcome these challenges and ensure that all CYSHCNs have equitable access to services in Douglas County.

There are great examples of strong collaboration occurring within Douglas County. For example, the Douglas County Mental Health Initiative, which was established in 2014 to unite community partners, address unmet mental health needs, connect people to mental health services and prevent those in need from falling through the cracks of the mental health system. Schools report having strong partnerships with hospitals, who provide professional development funds to implement school-based programming supporting the health and wellness of students. parks and recreation staff report regular meetings with the school district leadership regarding mental health teams and special education coordination to help one another stay current on school-based needs. There was expressed interest in continuing to grow this partnership and staying connected to continue to identify hurdles or gaps that can then be addressed together.

KIIs highlighted a strong desire for greater collaboration among county agencies, IDD services, parks and recreation departments, and community-based organizations. Greater collaboration was thought to be something that could help "families really feel like [they have] wraparound of support without it having to be wraparound." This may involve creating partnerships, coordinating services, and leveraging resources to better support the social and emotional well-being of children and staff. Collaborative efforts may include joint programs, shared resources, and coordinated outreach to ensure that available supports are effectively utilized and accessible to those in need. One tangible example shared by the KIIs of where collaboration may show up in the service delivery for CYSHCNs is with the DCHD application for Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and to what extent that may be an opportunity to connect people to other resources through the screening process.

Opportunities for Douglas County Health Department

Community members were asked to select the one strategy that resonates with them the most, suggesting areas of need or opportunities that reflected their experience. Figure 11 represents the percentage of individuals in the community who agreed that it was a priority.



Figure 11 Community Meeting Participant Resonance Check

Efforts for CYSHCNs to improve access to care, and address gaps in both caregiver supports and resources will need to involve a multi-faceted approach. This may include development of new resources while building awareness for existing resources, improving insurance coverage, expanding the availability of providers with expertise in caring for these children, improving transportation options, addressing language and cultural barriers, and improving coordination of care among providers and across different systems of care.

To address the identified challenges, KIIs and caregiver input suggest a need for DCHD to:

1. Take a comprehensive approach involving improved communication and collaboration, training and education programs, increased access to affordable services, supportive policies, and specific support for caregivers.
- 2. Recognize the critical role of caregivers and implementing caregiver support programs, respite care services, mental health resources, and caregiver education initiatives can significantly improve the well-being of CYSHCNs and their families.
- 3. Build awareness of available services and supports for caregivers and facilitate access to caregiver networks and support groups to provide vital resources and assistance.
- 4. Leverage the expertise of healthcare providers, schools, community organizations, and government agencies to enhance the support system for caregivers and contribute to the overall well-being of CYSHCNs through fostering greater coordination and collaboration.

DCHD plays an important role in increasing access to support for CYSHCNs in Douglas County. DCHD can collaborate with other community organizations, healthcare providers, and families to promote the health and well-being of CYSHCNs. Some of the specific ways that KIIs noted that DCHD may support CYSHCNs and their families include:

LEARN

DCHD can learn from CYSHCNs and their families regarding how they want to learn about and receive services and support, and how best to meet families where they are.

BUILD AWARENESS AND SHARE INFORMATION

DCHD can provide information about available services and support, as well as guidance on eligibility requirements and how to apply for benefits. A key role it needs to play is first building trust in the community.

CONVENOR

DCHD can facilitate learning and awareness building between County departments, service providers, schools, CBOs, and other family service entities.

COMMUNITY OUTREACH

DCHD can provide community outreach and education to raise awareness about the needs of CYSHCNs and the services and support available to them.

ADVOCATE

DCHD can advocate for policies and programs that support the needs of CYSHCNs and their families, including increased funding for healthcare services and support programs to help overcome the financial stress many families are feeling or expanded service hours to better accommodate children and family's school and work schedules.

UNIVERSAL PROGRAMMING

DCHD can identify where eligibility is a barrier to needed services and support and identify policies or approaches to ensure that these resources are more universal or open to all.

Appendix A: Community Key Informant Guide

Questions

1. Please tell us about your organization and how your work intersects with CYSHCNs.

Prioritization

Every five years, Colorado's Maternal and Child Health (MCH) Program conducts a state-level needs assessment of the health and well-being of women, children, youth and families to guide state and local public health work and to meet Title V MCH Block Grant requirements. The goal of the assessment is to gather information to understand what issues are facing this population and then to identify seven to ten specific priorities that can be positively impacted by public health work during the next five years. State and local MCH staff use the selected MCH priorities as a tool to focus efforts, align resources, and to positively impact in the lives of women, children and youth including those with special health care needs, and their families.

- 1. The CDPHE Maternal and Childs Health Advisory team identified 7 priorities in their 2021-2025 Title V Block Grant cycle. Among these priorities, what would be your top three priorities for DCHD to work on over the next five years? Why are these your top three priorities?
 - a. Create safe and connected built environments
 - b. Increase prosocial connection
 - c. Promote positive child and youth development
 - d. Improve access to supports
 - e. Increase social emotional well-being
 - f. Reduce Racial inequalities
 - g. Increase economic mobility
- 2. Would your priorities change if the focus was on an age group? If yes, which priorities and what age groups?
 - 0-5 years
 - 6-12 years
 - 13-18 years
 - 18-24 years
- 3. What is working well in Douglas County for CYSHCNs regarding their health, development, and well-being?
- 4. What do you think are the major health, development and well-being issues affecting CYSHCNs?
- 5. Are there any research, studies, assessments etc., that you recommend we consider for the needs assessment?

Accessing Care and Supports

- 6. Can you describe the process that a family with CYSHCNs goes through when attempting to access services in Douglas County? We know this is a big question, so please describe at a high level.
 - a. What are the points of entry?
 - b. What barriers exist in the current system of care?
 - c. What gaps exist in the current system of care?
 - d. What do you most frequently hear from parents/individuals/advocates about what needs go unmet? (If this different than what you observe in the system)
 - e. What is working in the current system of care? What would you not want changed?

Service Providers Questions

- 7. What are the barriers your experience as a provider to service delivery?
 - a. Service coordination between and among providers?
 - b. Eligibility for services?
 - c. Staffing?
 - d. Other Resources?
- 8. If family with a CYSHCNs presents at your service location, do you feel confident meeting their needs?
 - e. Why or why not?
 - f. If no what type of support do you need to be able to provide services to this population?
 - g. If no who could potentially provide those missing services?
- 9. Are there barriers to becoming a service provider or receiving reimbursement for your services?
 - a. Do you serve children youth and families in other counties?
 - b. Are there provisions that make it more or less difficult to be a provider in other locations?

Addressing Top Health Issues

- 10. If you could choose one intervention to improve the health and well-being of CYSHCNs, what would it be and why? These may be interventions that already exist but you may see a need for change in how your community accesses them or the ways in which they are delivered.
- 11. What are the barriers to offering these interventions in Douglas County?
 - Possible Prompts, if needed:
 - Funding
 - Lack of local policy support
 - Limited local resources
 - Lack of specialized training

- 12. What specific recommendations do you have for improving the health and well-being of CYSHCNs in Douglas County and overcoming these barriers?
 - Possible prompts, if needed:
 - *collect certain types of data to better understand an issue.*
 - reform or restructure an aspect of the service system.
 - improve availability, development, or quality of programs, including cultural competence of systems and services.
 - strengthen an existing policy that impacts health.
 - *share information with stakeholders to provide education about.*
- 13. Do you see a role for DCHD in these things? If so, describe.

Public Meeting & Focus Groups

We will conduct one public meeting in late May and a few focus groups to provide an opportunity to collect input to inform the assessment.

- 14. Where would you suggest we best meet families with CYSHCNs?
 - a. Do you know of any groups or meetings that currently take place that may be willing to include the needs assessment or have the needs assessment as their agenda item?
- 15. Do you feel there is a general preference for timing of the meeting (e.g. during the day, evenings, or weekend)?
- 16. Are there any other considerations we should keep in mind for the public meeting?

Closing

- 17. These are all the questions we have for you today. Does anyone have anything they would like to add that might've not been covered?
- 18. Thank you very much for your time and participation.

Appendix B: Caregiver Focus Group Discussion Guide

Introductions

Please tell us your name and how old your child is. If you feel comfortable answering this question: What medical problem or problems does your child have?
 a. What is a story of success for you, your family and child?

Prioritization of Issues

Every five years, Colorado's Maternal and Child Health (MCH) Program conducts a state-level needs assessment of the health and well-being of women, children, youth and families to guide state and local public health work and to meet Title V MCH Block Grant requirements. The goal of the assessment is to gather information to understand what issues are facing this population and then to identify seven to ten specific priorities that can be positively impacted by public health work during the next five years. State and local MCH staff use the selected MCH priorities as a tool to focus efforts, align resources, and to positively impact in the lives of women, children and youth including those with special health care needs, and their families.

2. [POLL] Among these priorities, what would be your top three priorities for DCHD to work on over the next five years? Why are these your top three priorities?

- a. Create safe and connected built environments
- b. Increase prosocial connection
- c. Promote positive child and youth development
- d. Improve access to supports
- e. Increase social emotional well-being
- f. Reduce Racial inequalities
- g. Increase economic mobility

Access to Supports and Services

- 1. Using just 1 to 3 words, how would you describe the access to non-medical/health supports and services that you or families you know have when getting care for a CYSHSN? Please feel free to use the chat or take yourself off mute to share.
 - a. Why did you select those words?
- 2. Using the chat function, please share the kinds of non-medical health supports and services do you or families you know currently use.
- 3. **[Chat function]** For this part of the discussion, we would like you to consider the services and supports in Douglas County for CYSHCNs. What services do you wish there were more of right here in Douglas County? Please select up to **three** services and supports.
 - Residential
 - o Home and community- based supports
 - Adult day
 - Non-emergency transportation
 - o Dental
 - Medical
 - o Mental health

- Crisis/emergency supports
- In-home respite
- Out-of home respite (temporary support)
- Educational services
- Clinical services (occupational therapy, physical therapy, speech/language
- therapy)
- o Vision services
- o Durable medical equipment
- Home modifications
- Early intervention (services for students 0-3 years)
- Pre-school special education (services for students 3-5 years)
- Infant services
- Recreational activities
- Other therapies (music, recreation)

a. Why did you select these top three services and supports? Explore the following:

i.Its available, and works well, but there isn't enough ii.It doesn't exist in Douglas county iii.Lack access – its too expensive, lack eligibility iv.Other reasons?

- 4. Where do you or families you know turn to when in need of services and support?
 - *[if do not mention schools]* Tell us about our experience access school-based supports.
 - Are these services in Douglas County or do you need to leave the county?
- 5. What <u>WORKS WELL</u> about the care and support you or families you know have for children, youth child and families?
- 6. What <u>DOES NOT</u> work well about the care and support you or families you know have for children, youth, and families?
- 7. What prevents you from getting what you need?
 - Prompts to include:
 - Lack of trained providers in my area
 - Affordability/financial limitations
 - Program/financial assistance qualifications
 - Lack transportation to service locations
 - Scheduling challenges
 - Waitlists
 - Providers are not sensitive to disability issues
 - Lack of Medicaid providers
- 8. Using the chat function, how do you learn about resources available to you, either as a caregiver of a CYSHCNs or for other needs in your life?

Access to Health Care

- 9. Using just 1 to 3 words, how would you describe the healthcare experience that you or families you know have when getting care for a CYSHSN? Please feel free to use the chat or take yourself off mute to share.
 - a. Why did you select those words?
 - b. Prompts: Wait times, provider availability, and insurance coverage

Care Coordination

- 10. [POLL] Where would you or families you know like more assistance? Select up to three.
 - Finding local services and supports
 - Planning and preparing for life transitions
 - Understanding a child's medical and behavioral health care needs
 - o Accessing care and schedule appointments with providers
 - o Coordinating communication across their child's health care team
 - \circ $\,$ Connecting to others who can address food, housing, and transportation needs

a. How would you want to get that assistance? What does the assistance need to look like?

Role of Douglas County Health Department

11. If you could choose one intervention to improve the health and well-being of CYSHCNs, what would it be and why? These may be interventions that already exist but you may see a need for change in how your community accesses them or the ways in which they are delivered.

Closing

These are all the questions we have for you today. Does anyone have anything they would like to add that might've not been covered?

Appendix C: Caregiver Survey

Douglas County Health Department is conducting a community scan focused on identifying existing resources and resource gaps for Children and Youth with Special Health Care Needs and their families.

CYSHCN: Children and youth who have more than one chronic condition for which they require healthcare services beyond what is generally required by children.

The voice of our community is very important to us as we develop programming to serve Douglas County families, like you! The survey will take about 5 minutes. We greatly appreciate your time in participating. Your privacy is important to us, all survey responses are anonymous. If you have any questions please contact Jean Newell | jnewell1@douglas.co.us | 303.263.5981

Caregiver Survey

- 1. Do you have a Child/Youth with Special Health Care Needs (CYSHCN)?
 - Yes
 - No
- 2. What is the age of your child with special health care needs?
 - 0-4
 - 5-12
 - 13-17
 - 18-24
- 3. What is your zip code?
- 4. Among the options below, what would be your top three priorities for Douglas County Health Department to work on over the next five years? Please select 3 options.
 - Create safe and connected built environments (e.g., homes, buildings, streets, open spaces, and infrastructure)
 - Increase prosocial connection
 - Promote positive child and youth development
 - Improve access to supports
 - Increase social emotional well-being
 - Reduce Racial inequalities
 - Increase economic mobility
- 5. Using only 1 to 3 words, how would you describe the experience that you have when getting services and supports for your child with special health care needs?
- 6. What services do you wish there were more of right here in Douglas County? Please select up to three services and supports. Please select 3 options.
 - Residential
 - Home and community-based supports
 - Adult day
 - Non-emergency transportation
 - Dental
 - Medical
 - Mental health
 - Crisis/emergency supports
 - In-home respite
 - Out-of-home respite (temporary support)
 - Educational services
 - Clinical services (occupational therapy, physical therapy, speech/language therapy)
 - Vision services
 - Durable medical equipment
 - Home modifications
 - Early intervention (services for students 0-3 years)

- Pre-school special education (services for students 3-5 years)
- Infant services
- Recreational activities
- Other therapies (music, recreation)
- 7. Why did you select these top three services and supports? (Check all that apply)
 - It's available, and works well, but there isn't enough
 - It doesn't exist in Douglas county
 - Lack access -example: it's too expensive, lack eligibility
 - Other
- 8. Who do you turn to when you are in need of services and support for your child with special health care needs?
 - Pediatrician / Primary care doctor
 - My child(ren) school
 - Friends and family
 - Douglas County Health Department
 - Online (google, social media, etc)
 - Other
- 9. What WORKS WELL about the care and support you or families you know receive for children, youth child and families?
- 10. What DOES NOT work well about the care and support you or families you know receive for children, youth, and families?
- 11. What types of resources do you use? (Check all that apply)
 - I do not need assistance
 - Case management or resource navigation
 - Childcare
 - Debt and credit counseling
 - Domestic violence assistance
 - Education (GED, ESL or post-secondary education)
 - Food assistance (WIC, SNAP, food banks, etc.)
 - Healthcare (including physical health and dental care)
 - Health Insurance (Medicaid, Medicare, etc)
 - Housing assistance
 - Job placement and training
 - Legal assistance
 - Mental health services
 - Senior programs and services
 - Services for the disabled (including those with physical and developmental disabilities)
 - Shelter (including temporary shelter or transitional housing)
 - Social and emotional support
 - Substance abuse treatment

- Transportation
- Utility assistance
- Veterans programs
- Other
- 12. What types of resources does your family need to access, but haven't yet? (Check all that apply)
 - I do not need assistance
 - Case management or resource navigation
 - Childcare
 - Debt and credit counseling
 - Domestic violence assistance
 - Education (GED, ESL or post-secondary education)
 - Food assistance (WIC, SNAP, food banks, etc.)
 - Healthcare (including physical health and dental care)
 - Health Insurance (Medicaid, Medicare, etc)
 - Housing assistance
 - Job placement and training
 - Legal assistance
 - Mental health services
 - Senior programs and services
 - Services for the disabled (including those with physical and developmental disabilities)
 - Shelter (including temporary shelter or transitional housing)
 - Social and emotional support
 - Substance abuse treatment
 - Transportation
 - Utility assistance
 - Veterans programs
 - Other
- 13. What barrier(s) have you experienced in getting services to support your child(ren) with special health care needs care and wellness? Select all that apply.
 - Forms were too complicated (Medicaid, Health Insurance or doctor's office/hospital forms etc.)
 - High out-of-pocket costs/it costs too much money
 - My child(ren) was not eligible for services
 - I could not find providers or services that understand, value and respect my culture
 - I could not find providers that looked like me or that speak my language.
 - I did not feel safe
 - I did not have health insurance
 - I did not know what services and resources were available
 - I do not have internet access or a device to use telehealth services

- Nothing has prevented me from getting services
- I felt embarrassed about asking for help and/or getting services
- Needed evening and/or weekend hours of service
- Needed service not offered in my area
- No appointments were available, or I couldn't get an appointment in a reasonable amount of time
- Not easy to travel to / I don't have transportation
- Poor physical access (i.e., handicap accessibility)
- I have not experienced any barriers.
- 14. Where would you or families you know like more assistance? Select up to three.
 - Finding local services and supports
 - Planning and preparing for life transitions
 - Understanding a child's medical and behavioral health care needs
 - Accessing care and schedule appointments with providers
 - Coordinating communication across their child's health care team
 - Connecting to others who can address food, housing, and transportation needs
 - Other
- 15. What other thoughts or feedback do you have for us?

Appendix D: Community Meeting PowerPoint Slides (Attachment)

HMA

Douglas County Health Department:

Children and Youth With Special Health Care Needs: Landscape Scan May 18, 2023





WELCOME

- >> About the Scan
- ≫ Findings
- » Reflection and Discussion
 - Is there anything additional you would share that you feel is not captured?
 - Within these key findings, what should be a priority?
 - What are the additional opportunities for Douglas County Health Department?
 - If you could choose one intervention for that priority area, what would it be and why?
 - What are the barriers to offering these interventions in Douglas County?
 - Who are the partners public health needs to have?

HOW TO ENGAGE

 \gg Jamboard <u>LINK</u>, which is anonymous

What questions do you have about the findings of the landscape scan? What feedback do you want to share?

- >> Use the chat function to ask questions or share your perspective
- »Raise your hand and take your self mute



CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN or "SHIN")

Children from birth to age 21 who have or are at an increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.





ABOUT THE LANDSCAPE SCAN: OBJECTIVES



WHAT IS PUBLIC HEALTH?

- Public health promotes and protects the health of people and the communities in the settings where they live, learn, work and play.
- While health care providers treat people who may be sick or have a health condition, people working in public health try to prevent people from getting sick or developing a condition in the first place.
- Public health practitioners also promote wellness by encouraging healthy behaviors and working to create conditions in which people can be healthy.

https://www.apha.org/What-is-Public-Health



COMMUNITY VOICE

- Informant group virtual interviews with key leaders (4 groups and 21 people)
- Caregivers of CYHSCN virtual focus groups (6 groups and 46 caregivers)
- Caregiver CYHSCN Survey open through May 22nd





Caregiver Perspective

Age of the CYSHCNs ranged from 4 to 17 vears

lealth care needs included Autism, Down Syndrome, asthma, intellectual disability, ADHD, physical disability

Community Leader Perspectives

School-based County Community based organizations IDD service provider Parks and Recreation





FINDINGS FROM THE LANDSCAPE **SCAN**

It is important to note that the information shared by the caregivers during the focus groups showed that there is no one "typical" caregiver and no one "typical" caregiver experience. Needs and expectations vary and can be constantly in flux.

WHAT IS WORKING WELL

- » There was a sense that when families are connected to services, it is a positive experience.
- >> The support of family and friends has been a significant factor in their success, with some reporting their children are doing better in school and making friends.
- >> The proximity of medical facilities has also been helpful for accessing necessary care.

The story of success about my child and my family is that most of the time my child has been accepted by many people, despite his conditions and a lot of people show us love here in the community.

My son is doing way better in school now and making more friends...this is such a big success because I remember praying for times like this.

WHAT IS WORKING WELL

- >> School-based Support:
 - > Implementation of inclusive policies and practices that support the educational success of CYSHCNs
 - >> Partnered with hospitals, for example, to implement Sources of Strength.
 - >> Professional development occurring in schools regarding trauma-informed practices and approaches, and restorative practices.
- >> Community-based Support:
 - Douglas County has a variety of community resources and organizations such as Developmental Pathways, the Arc of Colorado, the Special Olympics, and the Children's Hospital Colorado, which has a clinic in Highlands Ranch.
- >> Inclusive Parks and Recreation:
 - Douglas County has created inclusive parks and recreation programs that are accessible and welcoming to CYSHCNs. The County has built several playgrounds and facilities that are designed to accommodate children with disabilities.



14 *(number of votes among community leaders* Improve access to supports

10 Increase social emotional well-being

9 Increase prosocial connection

8

Create safe and connected built environments

6

Reduce racial inequalities/ Promote positive youth development

3

Increase economic mobility

WHAT IS NOT WORKING WELL: ACCESS TO CARE

»Caregivers often reported that accessing the care and support needed for their child was frequently noted as "frustrating" and "challenging".

Affordability of services and supports	Connecting to others who can address food, housing, and transportation needs	Discrimination in accessing care
Many families are unable to access care due to high healthcare costs, lack of insurance coverage, or inadequate financial assistance.	Not having basic needs met makes it difficult to attend medical appointments and access medical services.	Delays in care due to discrimination and inequitable access based on ethnicity and feeling like they are not receiving enough support. Children and families from diverse cultural and linguistic backgrounds may face challenges in accessing care due to language and cultural barriers.

WHAT IS NOT WORKING WELL: GAPS IN CAREGIVER SUPPORT

Caregivers in Douglas County :

- Struggle to find the right practitioner or specialist due to waitlists, appointment times, cost, and transportation concerns.
- Lack awareness of the full range of resources that are available to them.
- Navigating insurance and payment systems can be daunting and may prevent some families from accessing needed services.
- With increased understanding of a child's needs, knowing where to look and who to turn to becomes easier.

ment ncerns. f m.	Finding local services and supports	Understanding a child's medical and behavioral health care needs	Accessing care and schedule appointments with providers
t	Coordinating	Connecting to others	Planning and preparing for life transitions
sing	communication across	who can address food,	
a child's	their child's health care	housing, and	
I who	team	transportation needs	

WHAT IS NOT WORKING WELL: GAPS IN CAREGIVER SUPPORT

You just have to go around. Look for it. And it's difficult. Maybe the services are there, but it's difficult to know if they're there, and maybe even to find them.



At first really challenging, didn't know where to start, heard from a friend/family where to start, not knowing where I could get the support was really difficult.



Everything was taking a long time to do all the leg work on my own.

I feel like my issue is scheduling appointments...They could extend the working hours, or maybe during the weekend, even if it's just maybe till the afternoon.



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WHAT IS NOT WORKING WELL: GAPS IN RESOURCES

Caregivers were provided a list of resources and asked to share which of the list would they consider the top three source that they wish they was more of in Douglas County: Residential

Home and community- based supports Adult day Non-emergency transportation Dental Medical

Mental health Crisis/emergency supports In-home respite

Out-of-home respite (temporary support) Educational services Clinical services (occupational therapy, physical therapy, speech/language therapy) Vision services

Durable medical equipment Home modifications **Early intervention**

Pre-school special education (services for students 3-5 years) Infant services Recreational activities Other therapies (music, recreation)



WHAT IS NOT WORKING WELL: GAPS IN RESOURCES

Education, especially education for these kids like it's a little bit difficult for them to catch up in the Normal Schooling week...I can get the education services where my kid will be comfortable getting what he needs like where he's comfortable. - Caregiver

If someone wants to go in person, that's all the way in Littleton. If one of my families is in more rural Parker and they don't have a car, it is more difficult to access care. - KII



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NEED FOR MORE COLLABORATION AND COORDINATION

Community leaders highlighted a strong desire for greater collaboration among county agencies, IDD services, Parks and Recreation departments, and community-based organizations. Greater collaboration was thought to be something that could help *"families really feel like [they have] wraparound of support without it having to be wraparound."*

- Siloed mental health resources: Mental health services can be fragmented and disconnected, with little coordination between providers and organizations. Schools may also provide mental health services in isolation from the larger system of care.
- Limited communication between schools and parents: Parents of children with special healthcare needs
 may feel unheard by school staff, and there is a need to improve communication and collaboration
 between schools and families.
- Need for joint programs, shared resources, and coordinated outreach to ensure that available supports are effectively utilized and accessible to those in need.

OPPORTUNITIES FOR DOUGLAS COUNTY HEALTH DEPARTMENT

Learn

Public Health Contribution to Ensuring All Children and Families Who Live in Douglas County Thrive

DCHD can learn from CYSHCNs and their families about how they want to learn about and receive services and support, and how best to meet families where they are.

Build awareness and share information

DCHD can provide information about available services and support, as well as guidance on eligibility requirements and how to apply for benefits. A key role it needs to play is first building trust in the community.

Convenor

DCHD can facilitate learning and awareness building between County departments, service providers, schools, CBOs, and other family service entities.

Community outreach

DCHD may provide community outreach and education to raise awareness about the needs of CYSHCNs and the services and support available to them.

OPPORTUNITIES FOR DOUGLAS COUNTY HEALTH DEPARTMENT

Public Health Contribution to Ensuring All Children and Families Who Live in Douglas County Thrive

Advocate

DCHD could advocate for policies and programs that support the needs of CYSHCNS and their families, including increased funding for healthcare services and support programs to help overcome the financial stress many families are reported to be feeling or expanded service hours to better accommodate children and family's school and work schedules.

Universal Programming

DCHD could identify where eligibility is a barrier to needed services and support and identify policies or approaches to ensure that these resources are more universal or open to all.

Build Economic Opportunity

DCHD could create workforce opportunities for CYSHCNs to gain work experience.



POLL RESULTS

Did anything surprise you about the findings from the scan? (n=16)





POLL RESULTS

Of the key findings that need work, which <u>one</u> resonates with you the most? (n=17)



JAM BOARD



What questions do you have about the findings of the landscape scan?



What feedback do you want to share?





Discussion:

- Is there anything additional you would share that you feel is not captured?
- Within these key findings, what should be a priority?
- What are the additional opportunities for Douglas County Health Department?
 - If you could choose one intervention for that priority area, what would it be and why?
 - What are the barriers to offering these interventions in Douglas County?
- Who are the partners public health needs to have?



THANK YOU!!!

To share feedback on this community event, please take this survey.

