Title V Maternal and child health block grant 2025 Needs assessment

Children and youth with special health care needs

Division of Family Health
Office of Children with Special Health Care needs

Utah Department of Health & Human Services

Objectives

1. Overview of Utah Department of Health and Human Services (DHHS) Title V Maternal and Child Health Block grant 2025 Needs Assessment for children and youth with special health care needs (CYSHCN).
2. Review prioritization and needs identified from community and provider surveys for CYSHCN.
3. Review needs identified from CYSHCN caregiver survey and focus groups.
4. Discuss DHHS recommendations.
5. Group discussion.

Overview

The 2025 Title V MCH Block grant CYSHCN Needs Assessment captured experiences and needs of Utah children and youth with special health care needs and their families through:

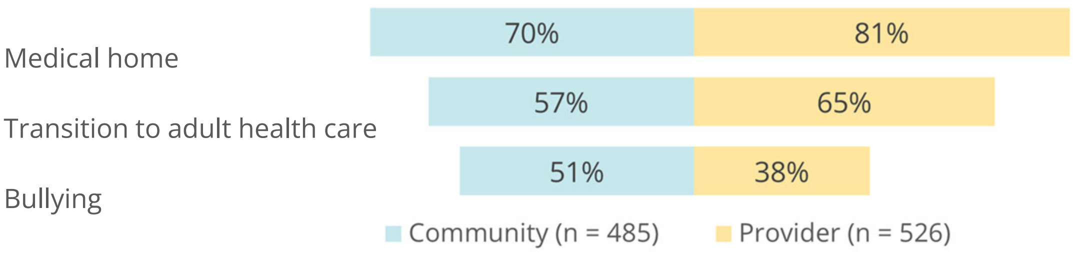
- Community and provider surveys (n = 1,011)
- Caregiver of a child of youth with special health care needs survey (n = 731)
- Ten Focus groups conducted through the Utah Parent Center (n = 56 participants)

CSHCN health - NPM rankings overall

Medical home was the highest ranked NPM overall.

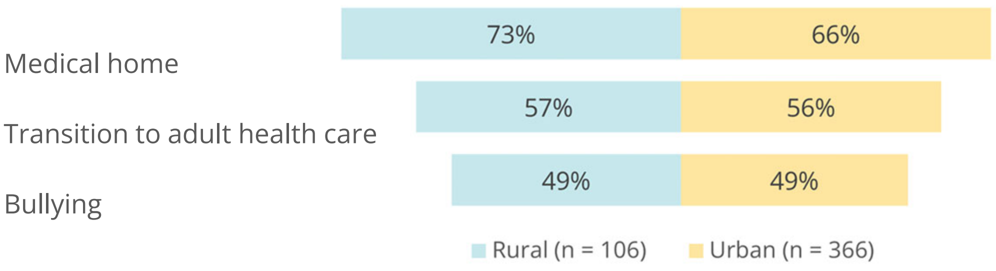
CSHCN health - NPM rankings for community members and providers

Community members and providers ranked NPMs similarly.



CSHCN health - NPM rankings for rural and urban areas

Rural and urban community members ranked NPMs similarly.



CSHCN health - NPM rankings by race and ethnicity

Community members of different racial and ethnic groups ranked NPMs similarly.

Top NPMs for non-Hispanic non-White community members (n = 46):

1. Medical home (65%)
2. Transition to adult healthcare (63%)
3. Bullying (46%)

Top NPMs for Hispanic community members (n = 134):

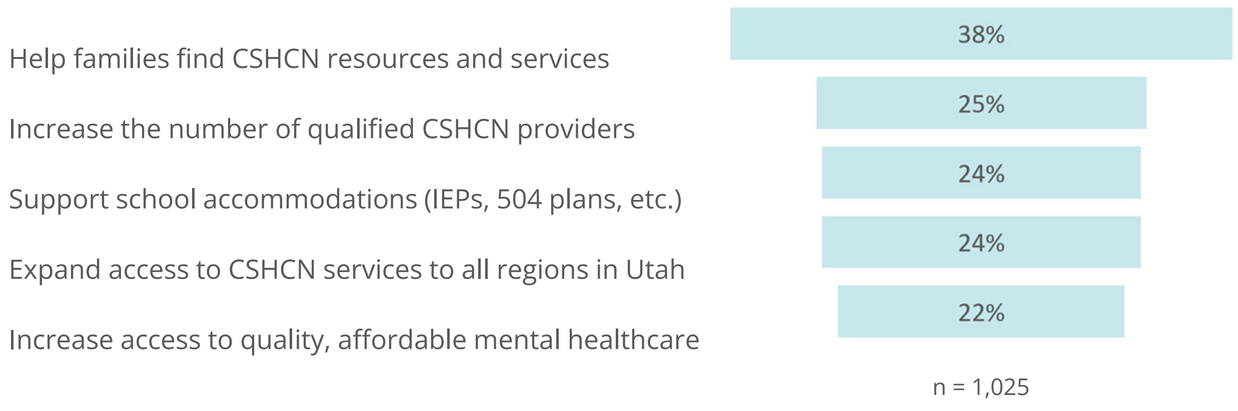
1. Medical home (58%)
2. Transition to adult healthcare (52%)
3. Bullying (52%)

Top NPMs for non-Hispanic White community members (n = 318):

1. Medical home (71%)
2. Transition to adult healthcare (54%)
3. Bullying (48%)

CSHCN health - other issue rankings overall

Helping families find CSHCN resources and services was ranked highest overall.



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CSHCN health - other issue rankings for rural and urban areas

Top other issues for rural community members (n = 106):

1. Finding CSHCN resources and services (33%)
2. More qualified CSHCN providers (26%)
3. CSHCN service access in all regions in Utah (23%)
4. More community-based services (26%)
5. Healthy, affordable food (26%)

Top other issues for urban community members (n = 366):

1. Finding CSHCN resources and services (33%)
2. School accommodations (IEPs, 504 plans, etc.) (27%)
3. Healthy, affordable food (25%)
4. More qualified CSHCN providers (21%)
5. Safe, stable, affordable home (20%)

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CSHCN health - other issue rankings by race and ethnicity

Top other issues for non-Hispanic non-White community members (n = 46):

1. Healthy, affordable food (35%)
2. Safe, stable, affordable home (26%)
3. More qualified CSHCN providers (24%)
4. School accommodations (22%)
5. Adequate and continuous insurance coverage (22%)
6. Quality, affordable medical care (22%)

Top other issues for Hispanic community members (n = 134):

1. Finding CSHCN resources and services (33%)
2. School accommodations (24%)
3. Healthy, affordable food (24%)
4. High-quality, affordable mental health care (20%)
5. More qualified CSHCN providers (19%)

Top other issues for non-Hispanic White community members (n = 318):

1. Finding CSHCN resources and services (34%)
2. School accommodations (26%)
3. Healthy, affordable food (24%)
4. Adequate and continuous insurance coverage (24%)
5. CSHCN service access in all regions in Utah (22%)

Caregivers of children and youth with special health care needs Title V needs assessment

The caregiver survey was created using multiple resources, such as questions from the 2022 National Survey of Children's Health and incorporation of the *Blueprint for Change* proposed by AMCHP and HRSA Maternal and Child Health Bureau. Feedback from staff within the Office of CSHCN, the Utah Parent Center, and other stakeholders were incorporated into the survey.

Overview of the caregiver survey

Section I: Experiences with health care services and resources

A. Blueprint for Change questions
B. Diagnoses
C. Insurance coverage
D. Medical home
E. Difficulties and barriers accessing care, equipment, and services
F. Transition to adult health care

Section II: Demographic information

Who responded

Among the 731 total respondents:

- 484 have or care for 1 child with special health care needs.
- 227 have or care for more than one child with special health care needs.
- 20 were an adult with a special health care need.

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Diagnosis by age group

Anxiety, autism spectrum disorder, and sensory processing disorder were the most common diagnoses reported by caregivers (n = 731). However, a higher percentage of younger children (0 to 5 years) had been diagnosed with a developmental disorder, whereas older children (6+ years) were diagnosed with a behavioral or emotional disorder more frequently.

0 to 5 years (n = 100):

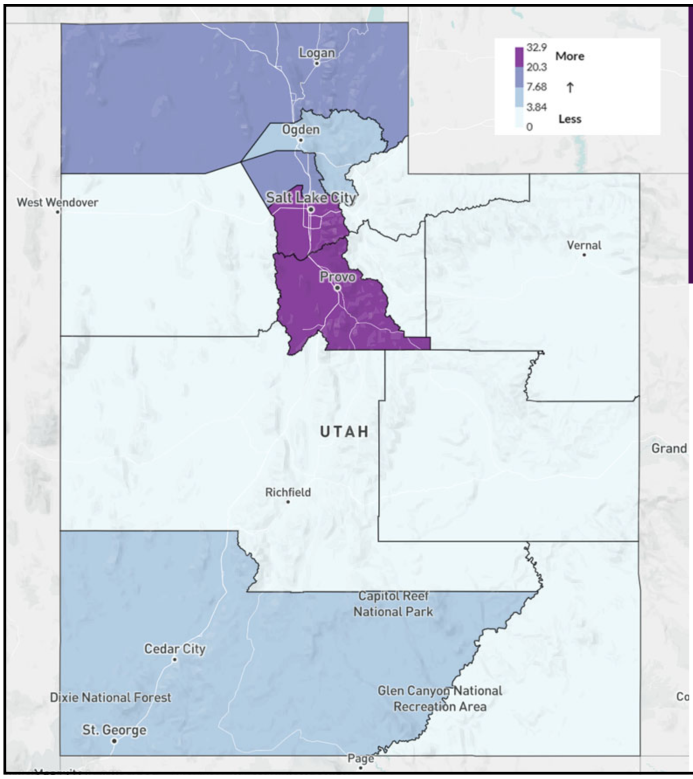
1. Speech delay (55%)
2. Autism spectrum disorder (49%)
3. Developmental delay (48%)
4. Sensory processing disorder (43%)
5. Communication disorder (30%)

6 to 11 years (n = 156):

1. Anxiety (68%)
2. Sensory processing disorder (63%)
3. Autism spectrum disorder (62%)
4. Attention deficit disorder (ADD or ADHD) (61%)
5. Speech delay (52%)

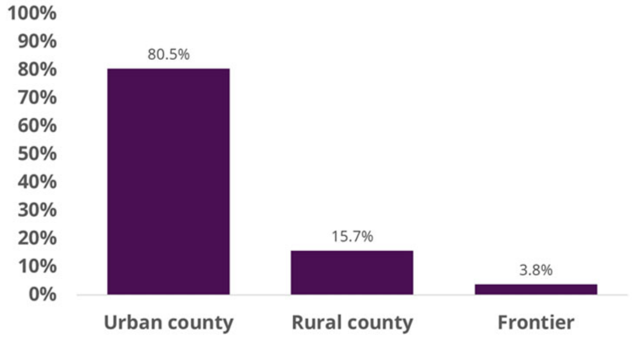
12+ years (n = 341):

1. Anxiety (71%)
2. Autism spectrum disorder (64%)
3. Attention deficit disorder (ADD or ADHD) (58%)
4. Intellectual disability (57%)
5. Sensory processing disorder (56%)



The majority of respondents live in urban areas. 12 out of 13 local health districts were represented in survey responses

Percentage of respondents by residence classification (n = 553)



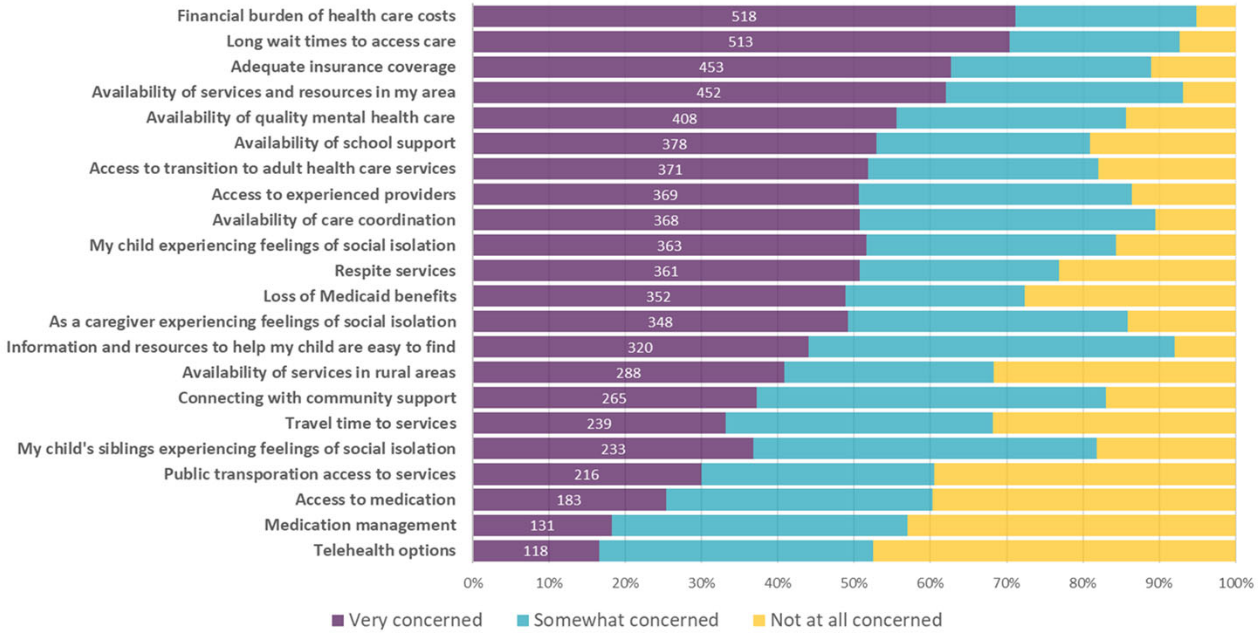
Blueprint for change

A national framework for a system of services for children and youth with special health care needs (CYSHCN) where they enjoy a full life and thrive in their community from childhood through adulthood by focusing on health equity, quality of life, access to services, and financing of services.

Caregivers top concerns

1. Financial burden of health care costs.
2. Long wait times to access care.
3. Adequate insurance coverage.
4. Availability of services and resources in their area.
5. Availability of quality mental health care.

“How concerned are you to the following?”



Blueprint for change: by residence

"Very concerned" for urban caregivers (n = 445):

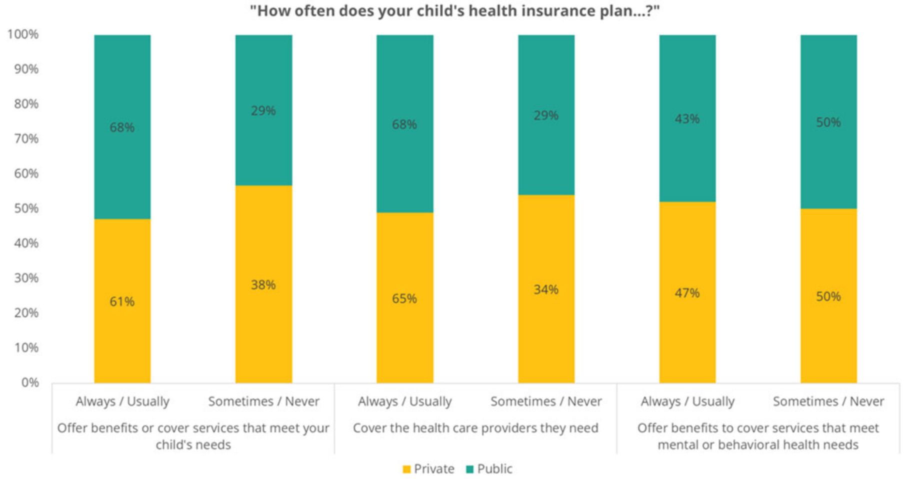
1. Financial burden of health care (71%)
2. Long wait times to access care (70%)
3. Adequate insurance coverage (63%)
4. Availability of services and resources in your area (58%)
5. Availability of quality mental health care (57%)

"Very concerned" for frontier and rural caregivers (n = 108):

1. Availability of services and resources in your area (75%)
2. Long wait times to access care (68%)
3. Financial burden of health care costs (67%)
4. Availability of school support (61%)
5. Availability of quality mental health care (58%)

Insurance coverage

A high percentage of respondents' children are enrolled in a health insurance plan (98.4%) with a majority of plans offering benefits or covering services "usually" or "sometimes". There were no notable differences between public and private health insurance plans and respective coverage "always/usually" or "sometimes/never".



National performance measure: Medical home

A medical home is an approach to providing comprehensive and high-quality primary care. A medical home should be accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally-effective.

Medical home is evaluated through the percentage of children and youth with special health care needs that:

- Have a personal doctor.
- Have a usual source of sick care.
- Experience family-centered care.
- Are able to receive referrals for services.
- Receive care coordination services.

National performance measure: Medical home

Personal doctor

- 91.5% had at least one personal doctor.

Usual source of sick care

- 76% have a place or another caregiver they usually take their child when sick.

Referral services

- 70.6% needed a referral to see any doctor or receive any other service.
- 60% of those that needed a referral said it was somewhat or very difficult to get a referral.
- 2.3% reported it was not possible to get a referral.

Family-centered care

Respondents felt that their child's provider "always" or "usually":

- Spent enough time with them and their child during appointments (77.1%).
- Listened carefully to the parent or guardian (77.7%).
- Listened carefully to their child (72.3%).
- Showed sensitivity to their family's values and culture (84.4%).
- Provided specific information concerning their child's care (74.3%).
- Helped them feel like a partner in their child's care (78%).

Care coordination

- 61% could have used extra help coordinating their child's care of which 46.6% received help "sometimes" and 29.9% "never" received help.

National performance measure: Medical home
Care coordination

Care coordination is a patient-and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes[3].

61%	Felt they could have used extra help arranging or coordinating their child's care with the different health care providers or services they need.
24%	Felt they always or usually got as much help as they wanted with arranging or coordinating their child's care.
26%	Were aware that their child's doctor and other health care providers communicate about their child's care.

27% of respondents said they received care coordination from someone other than themselves. Primary health providers (13.1%), Division of Services for People with Disabilities (9.4%), and school/school districts (7.6%) were the most common sources of care coordination for these people.

National performance measure: Transition to adult health care

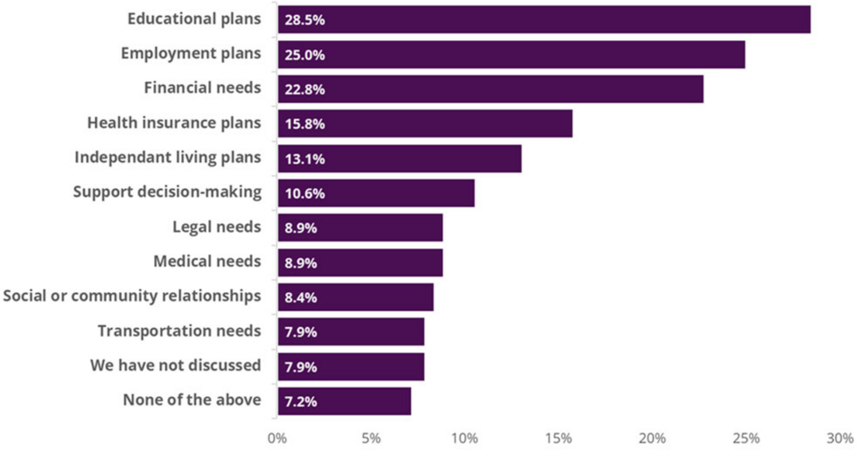
Transition to adult health care is the process of moving a child to an adult, patient-centered model of health care[2] and is measured as the percentage of youth, ages 12 to 17, that received services to prepare for the transition to adult health care.

63%
of respondents said they or their child have a special health care need and are 12 years of age or older.

National performance measure: Transition to adult health care

31% of caregivers said their child's doctor or other health care provider talked to them about when their child will need to see doctors or other health care providers who treat adults.

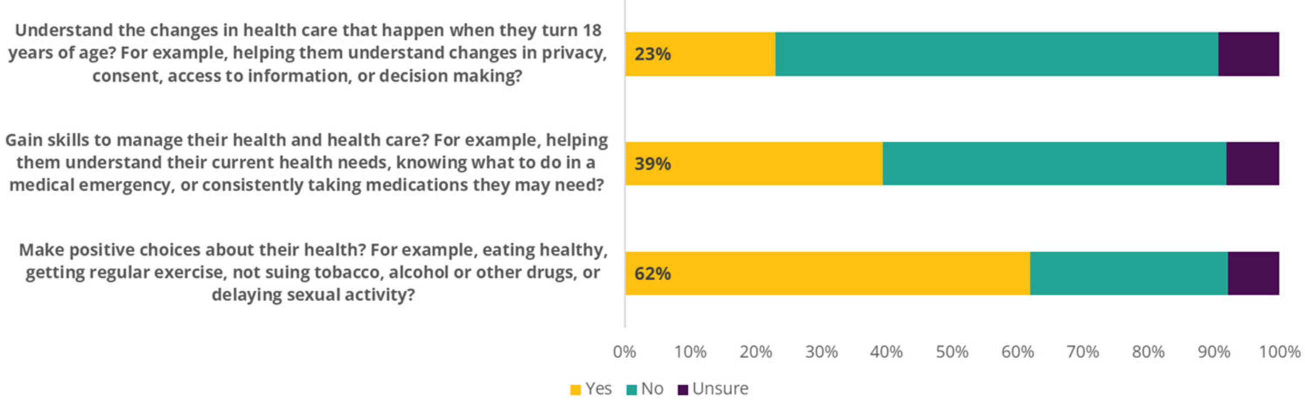
17% of caregivers said their child's health care providers addressed transitioning to adult health care by discussing an adult care plan.



Which of the following topics have you and your child discussed with your doctor or health care provider about transition to adult care? (Select all that apply)

National performance measure: Transition to adult health care

Has your child's doctor or health care provider actively worked with your child to do the following?



Barriers

Nearly half of respondents said their child had a hard time getting equipment (36%) or an appointment (48%) with any health care provider in the last 12 months.

"We have to wait months for an appointment because there are so many people here competing for the same services."
(Urban focus group participant)

"It's lonely out here. I don't know any other parents going through what I am, and it's hard to find support."
(Rural focus group participant)

"I feel like we're at the mercy of whoever is available. Sometimes we drive hours only to find out the specialist canceled."
(Rural focus group participant)

"Sometimes we feel like second-class citizens because no one understands our language or culture."
(Spanish-speaking participant)

Difficulties accessing services and resources

Caregivers said that in the last 12 months they had the most difficulty accessing mental health providers, prescription medicines, and recreational and social opportunities.

Health care providers (n = 295):

1. Mental health provider (47.5%)
2. Behavioral therapist (34.9%)
3. Physical, occupational, or speech therapist (34.2%)
4. Neurology (21%)
5. Psychiatry (21%)

Equipments and/or prescriptions (n = 226):

1. Prescription medicines (78.3%)
2. Durable medical equipment (28.3%)
3. Sensory items (18.1%)
4. Mobility aids or devices (15%)
5. Diapers (13.3%)

Services (n = 614):

1. Recreational and social opportunities (41.2%)
2. Respite care (38.1%)
3. Applied behavioral analysis therapy (28.5%)
4. After school programs (24.1%)
5. Parent support groups (24.1%)

Barriers accessing services and resources

Caregivers said that waiting lists, financial costs, and unavailability of providers were the largest barriers to accessing services and resources for their child.

Health care providers (n = 308):

1. No appointments were available (60.1%)
2. Put on a waiting list (58.4%)
3. Provider wasn't available (34.1%)
4. Insurance did not cover services (31.2%)
5. There are no experienced or qualified providers near me (23.7%)

Equipments and/or prescriptions (n = 215):

1. Insurance didn't cover it (54%)
2. It was not available (50.2%)
3. Could not afford it, even with insurance (27.4%)
4. The provider didn't coordinate my child's care (17.7%)
5. Not eligible to receive it (10.7%)

Services (n = 456):

1. Put on a waiting list (47.8%)
2. Services were not available (46.9%)
3. Lack of guidance or unsure who to contact for services (45.8%)
4. Insurance did not cover or limited insurance coverage (41.2%)
5. Could not afford services (39.9%)

Barriers accessing services and resources

Difficulties and barriers to accessing services and resources differed among caregivers living in rural and frontier areas, as well as those on public health insurance.

Caregivers living in rural and frontier areas more frequently reported:

- Difficulties accessing certain medical services (dental care, genetic counseling, and audiology).
- Finding community groups and transition to adult health care services.

Barriers due to lack of experienced providers in their area, services not provided in their area, far travel times, and unavailability of telehealth were significantly higher than urban responses.

Caregivers whose child has public insurance more frequently reported:

- Difficulties accessing social support opportunities, such as recreational activities, parent support groups, and afterschool programs.
- Accessing clinical services such as care coordination and dental care.

Lack of guidance and coordination of finding services and transportation barriers were more common among those on public health insurance.

Title V State Needs Assessment focus groups

Between August 2024 and December 2024, the Utah Parent Center (UPC) held 10 focus groups with 56 parents and caregivers of CYSHCN.

Dominant themes from focus groups

- Navigating complex systems
- Financial burdens
- Barriers to equitable care
- Stigma surrounding disabilities and mental health
- Transition to adult health care services
- Differences between challenges faced in certain communities

Systems of care and access

- Frustration with navigating complex systems of service providers and lack of streamlined communication between agencies.
- Geographic isolation within rural communities vs. system overload within urban communities.

Quality of life and well-being

- High levels of stress and burnout with inadequate support systems.
- Stigmatization, insufficient inclusion programs, and lack of community resources.

Financing

- Indirect and direct costs of care are a significant barrier, such as insurance limitations, out-of-pocket expenses, complicated Medicaid processes, and travel expenses.

Health equity

- Societal stigmatization, exclusion despite diversity, and increased social isolation.
- Feeling “forgotten” by policymakers and service planners.

Transition to adult healthcare

- Challenges: lack of planning and support, limited adult services, financial strain, employment challenges, social isolation, and caregiver burnout.
- Strengths: strong school support for transition planning, access to vocational training programs, supportive community organizations, telehealth and remote services, peer networks and parent support groups, and advancements in assistive technology.

Insights from Spanish-speaking groups

- Challenges worsened by language barriers and lack of cultural humility.

Summary of findings

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- Medical home was the highest ranked NPM between community members and providers.
    - Results from caregiver survey and focus groups indicate frustration with the lack of care coordination and difficulty navigating complex systems.
- Resources and services that serve CYSHCN are difficult to find and not centralized.
- Financial strains are a major challenge for families who have a child or youth with special health care needs, regardless of insurance coverage.
- Transition to adult health care services and resources, as well as having access to knowledgeable providers, are lacking.
- Both caregivers and CYSHCN frequently experience feelings of social isolation, stigmatization, and lack of community support and social opportunities.
- While needs are similar across Utah, certain communities experience different challenges and require solutions that fit their needs specifically.

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DHHS recommendations

CSHCN domain:

- Transition to adult healthcare
    - Lack of providers who are educated and equipped to deliver transition to adult health care resources and services.
    - Inadequate care coordination for CYSHCN extends to both medical home and transition to adult health care NPMs.
- Medical home
    - Addressing root causes and potential for impact.
    - Consistent high priority across community, provider, and CSHCN parent surveys as well as across race/ethnicity.
    - High potential to address other concerns identified in the MCH Needs Assessment survey.

UTAH TITLE V BLOCK GRANT
BREAKOUT SESSION
DISCUSSIONS

Children with Special Health Care Needs
Facilitator: Logan Waechtler

HEALTH
UNIVERSITY OF UTAH

March, 2025

DISCUSSION QUESTIONS

1 What are your thoughts about the results? **What are one or two of your top priorities or issues you would like to discuss?**

2 What do you think about the UDHHS recommendations? **Do you support the direction?** Are there other more important priorities?

3 **What do you recommend?** What **strategies** are needed for complex systems change? Are there **opportunities** (or low-hanging fruit) that could be addressed sooner than later? How?

4 **Who needs participate?** What is your/your agency's role in any of these areas? Are there existing partnerships that need to expand? New partnerships needed?

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