

Health Equity For New Mexico's Children: Children and Youth With Special Health Care Needs

Policy Brief

October 2019



This is the first of three policy briefs examining issues surrounding health equity among children and youth in New Mexico. The second will examine children who experience adverse childhood events, while the third will focus on the intersection of special health care needs and adverse childhood events.

Findings reported in these briefing papers are based on data from the combined 2016 and 2017 National Surveys of Children's Health (NSCH). The survey is sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration and administered by the U.S. Census Bureau. The NSCH examines the physical and emotional health of children and youth birth to seventeen as well as the prevalence of special health care needs among children. Surveys are completed by a parent of the child or youth with and without special health care needs.

Children and youth with special health care needs (CYSHCN) are people 17 and younger who have one or more chronic conditions, including physical health problems, behavioral health issues and/or physical or developmental disabilities. In New Mexico, 19%, or nearly 94,000 children, were identified as having special health care needs, about the same percentage as the nation as a whole (18.8%).

Physical health problems include asthma (28%), frequent severe headaches or migraines (7%), genetic conditions (8%) or epilepsy or seizure disorders (5%). Behavioral health issues include depression (15%) and anxiety (23%). Disabilities include learning disabilities (19%), intellectual disabilities (8%), and communication difficulties (20%).

Children and youth with special health care needs typically require higher levels of health and social services than children without. 65%, or 61,000 of these children, have two or more conditions. Managing health care and other services for multiple conditions presents an additional challenge for both families and service delivery systems.

According to the Robert Wood Johnson Foundation,¹ health equity “means that everyone has a fair and just opportunity to be as healthy as possible”. Moving towards health equity requires removing obstacles to health.

What obstacles to health equity exist for the nearly 100,000 children in the state with special health care needs? What gaps in policies, programs and services need to be addressed?

Summary

- New Mexican children with special health care needs face greater economic hardship.
- More New Mexican CYSHCN come from minority communities.
- Families of CYSHCN use child care at about the same rate as those without, but change jobs or don't take a job more frequently because of difficulties getting child care.
- More CYSHCN have health insurance and a medical home and use more health care than non-CYSHCN.
- CYSHCN are five times less likely to receive needed health care and face greater difficulty in getting referrals, care coordination and the health care they need.
- Parents of children and youth with special health care needs are in poorer health.
- Children with special health care needs experience more adverse childhood experiences (ACEs), which can lead to life-long negative consequences.
- Resiliency is an important mechanism to improve health equity for children and youth with special health care needs.

New Mexican Children with Special Health Care Needs Face Greater Economic Hardship

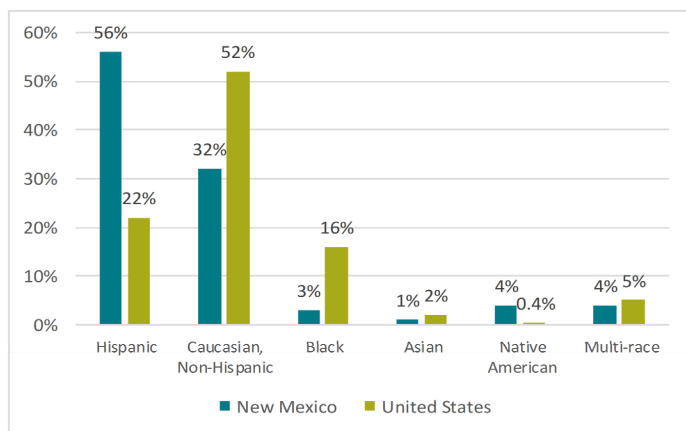
- 21% of CYSHCN in New Mexico live in working poor households - households in which parents are employed full-time but earn less than 100% of the federal poverty level - as opposed to only 14% of New Mexican children without special health care needs.
- 20.5% of parents of CYSHCN in New Mexico reported having to cut back hours or stop working completely due to their child's health status, compared to only 2.2% of parents of children without special health care needs.

More New Mexican CYSHCN Come from Minority Communities than in the United States

- New Mexico is a racially and ethnically diverse state, with Hispanics comprising 49% of the population, Caucasian non-Hispanics 37%, and Native Americans 11%.
- New Mexican children with special health care needs reflect this diversity compared to CYSHCN nationally (see **Figure 1**). They are predominately more Hispanic (56% versus 22% nationally); less Caucasian (32% versus 52% nationally); less African-American (3% versus 18%); and more Native American (4% versus 0.4%).

Figure 1

Racial and Ethnic Composition of CYSHCN in New Mexico and Nationally



More CYSHCN Have Health Insurance and a Place They Usually Get Health Care. They also Use More Health Care and Face Greater Difficulty in Getting Referrals, Specialist Care, and Care Coordination

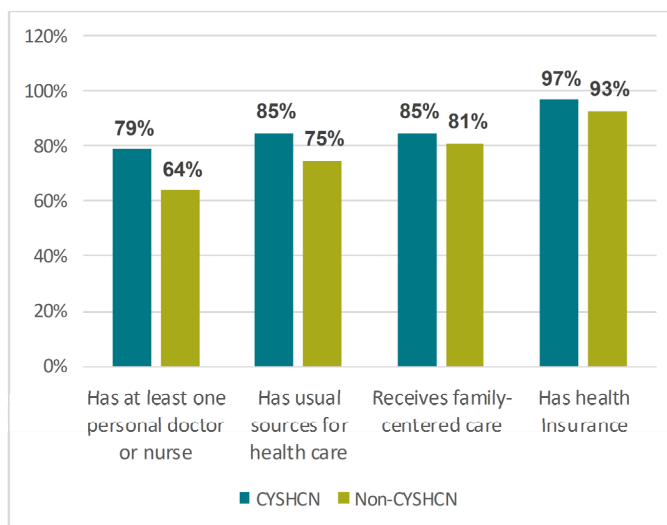
- The goals of the medical home model include health care that is family-centered, coordinated, and gives access to a regular source of care, insurance, and preventive, primary and specialty care.
- More CYSHCN have at least one health care provider,

a place they usually get health care, and report receiving family-centered care (see **Figure 2**).

- 97% of CYSHCN in the state had health insurance, but more - 61% - are insured through public plans (primarily Medicaid but also the Indian Health Service), as opposed to 47% of non-CYSHCN.
- 27% of CYSHCN in the state had at least one annual visit to an emergency room compared to 18% of New Mexican children who are not.

Figure 2

Elements of the Medical Home for CYSHCN and Non-CYSHCN in New Mexico

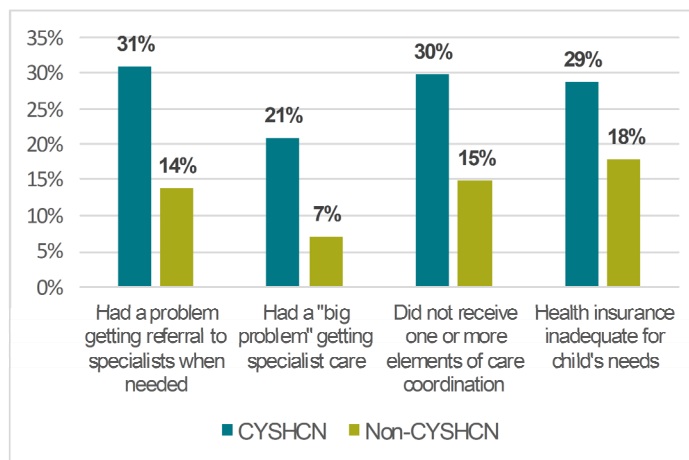


However, parents of CYSHCN report encountering more barriers in key elements of the Medical Home than parents of non-CYSHCN (see **Figure 3**).

- Over twice as many CYSHCN in the state - 31% - reported having problems getting referrals to specialists than non-CYSHCN (14%).

Figure 3

CYSHCN Face More Barriers in Key Elements of the Medical Home



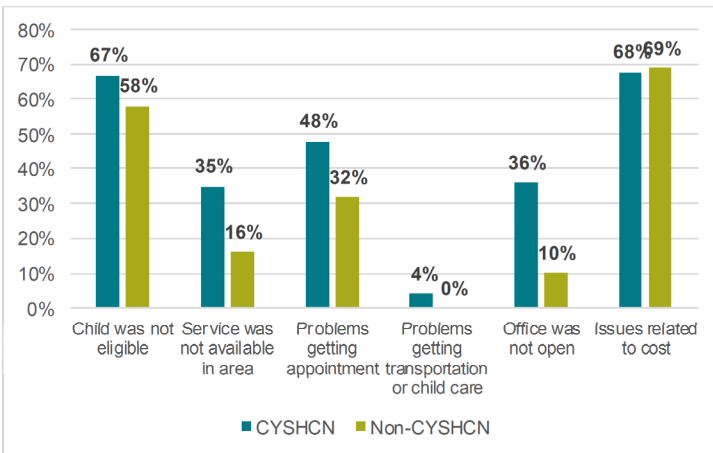
- Of CYSHCN who sought specialist care in New Mexico, 21% reported that they had a “big problem” accessing specialist care versus only 7% of non-CYSHCN.
- 30% of CYSHCN reported not receiving one or more elements of care coordination versus 15% of non-CYSHCN.
- 29% of families of CYSHCN said that their health insurance was inadequate for their child’s needs as opposed to 18% of families of non-CYSHCN.

CYSHCN in New Mexico Are Five Times Less Likely to Receive Needed Health Care

Figure 4 highlights barriers faced by CYSHCN in receiving needed health care. Significantly more CYSHCN:

- Were ineligible for services than non-CYSHCN;
- Faced greater difficulty finding health care in their geographic area;
- Had more difficulty locating health care offices that were open when the child needed care; and
- Faced greater difficulty getting both needed appointments and transportation.

Figure 4
Barriers to Accessing Health Care for CYSHCN and Non-CYSHCN in New Mexico



Parents of Children With Special Health Care Needs Are in Poorer Health Than Parents of Non-CYSHCN

While 59% of New Mexican mothers of children without special health care needs said that their health was good or excellent, only 36% of mothers of children with special health care needs in the state reported being in good or excellent health.

The difference for fathers was not as pronounced. 57% fathers of children with special health care needs reported being in good or excellent health, while 63% of fathers of

children without special health care needs said that their health was good or excellent.

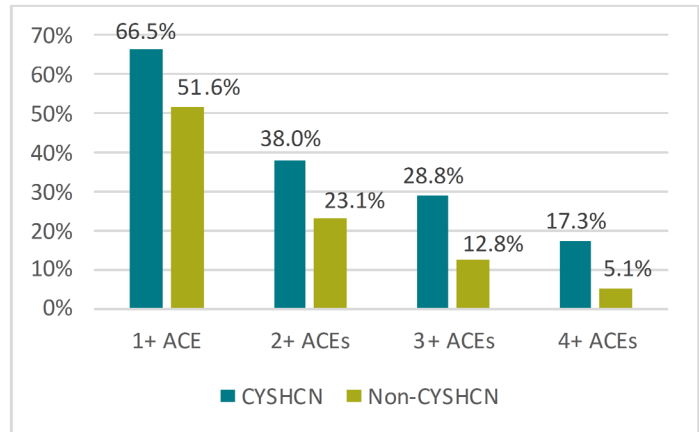
Children With Special Health Care Needs Experience More Adverse Childhood Experiences (ACEs), Which Can Lead to Life-Long Negative Consequences

Adverse Childhood Experiences (ACEs) are potentially traumatic experiences faced by children in the household including abuse and neglect, divorce, substance abuse, domestic violence, and bullying.

The experience of ACEs can have long-term negative impacts, including lower educational success; higher rates of physical and psychological illness; higher health care costs; higher rates of risk behaviors including depression, obesity and smoking; and more interactions with the criminal justice system. The prevalence of ACEs is substantially higher for children with special health care needs (Figure 5).

- New Mexican children with special health care needs experience ACEs at significantly higher rates than children without. 67% of CYSHCN experienced one or more ACEs compared to 52% of non-CYSHCN. 17% of CYSHCN experienced four or more ACEs compared to 5% of non-CYSHCN.
- 19% more CYSHCN in the state lived with someone who was mentally ill, suicidal, or severely depressed than non-CYSHCN, and 12% more CYSHCN than non-CYSHCN had lived with someone who had a problem with alcohol or drugs.

Figure 5
Adverse Childhood Experiences in CYSHCN & Non-CYSHCN



Resiliency is an Important Mechanism to Improve Health Equity for CYSHCN

Resiliency - factors that help children rebound from challenges and adversity - can help overcome the negative impact of potentially traumatic events such as adverse childhood experiences.

One type of resiliency called “family resiliency” focuses on factors such as families solving problems together, staying hopeful in times of stress or difficulty, and being able to talk together as a family about important topics. New Mexico families with CYSHCN compared favorably on a number of aspects of family resiliency.

- Reading to children on a regular basis is an indicator of resiliency.² 44% of CYSHCN in the state between birth and five were read to every day in a week compared to 36% of non-CYSHCN in the state, while 54% were sung to every day in a week compared to 47% of non-CYSHCN in the state.
- Another important resiliency factor is parents participating in their child’s activities.³ 70% of New Mexican parents of children with special health care needs participated in their child’s events or activities compared to 60% of parents of non-CYSHCN in the state.

Moving Towards Health Equity for Children and Youth With Special Health Care Needs in New Mexico: Gaps in Policies, Programs, Services and Knowledge

The findings in this Policy Brief have identified five system-level issues that need attention from policymakers, social service agencies, and the public health community in order to move towards health equity for children and youth with special health care needs. These issues dovetail with those identified as issues on the national level in the 2019 report by the National Academies of Science, Engineering and Medicine *Vibrant and Healthy Kids: Aligning Science, Practice, and Policy to Advance Health Equity*.⁴

More Information is Needed About the Intersection of Special Health Care Needs and Adverse Childhood Experiences

Children with special health care needs experience significantly more adverse childhood events than children without. Too little is known about the intersection of these, including the impact on children and families who face both chronic health conditions and potentially traumatic childhood experiences. We also have too little information on how - or if - health and other service systems that provide programs and services to these two groups coordinate care or share information.

Consider How to Better Meet the Health Needs of Parents of Children with Special Health Care Needs

More parents of CYSHCN - particularly more mothers - report being in poorer health than parents of non-CYSHCN. Having both a child and a parent in a family who have health issues affects the entire family unit.

Families of CYSHCN are frequently stretched to meet their child’s complex medical care issues, leaving many physical and psychosocial health issues in family members unaddressed. It is too easy for the health needs of family members to be overlooked in the quest to provide services to the child.

More information is needed about the health impacts on family members of CYSHCN, what types of programs or services are available or can be developed to address those needs, and how separate health care systems providing care to children and parents can be coordinated.

Families of CYSHCN Need Assistance to Ensure That They Participate in Programs That Help Reduce the Effects of Poverty

Poverty has long been known to be a determinant of health for all individuals. However, many children with special health care needs in the state live in families facing considerably greater economic hardship. Care must be taken to ensure that these children and their families do not slip through the cracks of programs and services intended to alleviate the worst effects of poverty.

In many cases, health care programs do not coordinate their efforts with social service programs. One approach to increase coordination that could serve as a potential model is the care coordination provided to approximately 4,000 CYSHCN in the state by Children’s Medical Services.

Care coordination in this program includes but goes beyond medical case management to assist families in identifying and accessing programs that help reduce the worst effects of poverty, including social and other services such as transportation and food banks, as well as programs such as the Supplemental Nutrition Assistance Program (SNAP), Medicaid, SSDI and others. All of these programs are beneficial in reducing the effects of poverty.

Increase Resources Devoted to Medical Homes and Specialty Care Coordination so More CYSHCN can Receive the Health-Related Services They Need

New Mexico children with special health care needs face significant challenges in accessing the health care they need, including referrals to specialty care. One way to improve access is to more fully implement the concept of medical homes for these children. This includes increasing the availability of specialty care, finding ways to improve the process of getting referrals, and addressing transportation barriers.

In New Mexico, integrated, family-centered care coordination for CYSHCN is provided to over 4,000 children from birth to 21 by Children’s Medical Services in the Family Health Bureau of the Department of Health. Over 60 clinical social workers and other staff provide both medical and social service coordination, and provide over 160 specialty outreach clinics across the state.

...[T]he odds of positive or negative health are never fixed; individual exposures, experiences, resilience, and choices help set and adjust them over time. Advancing health equity requires...systems-level changes, including changes to laws and policies and investment of resources.

Vibrant and Healthy Kids: Aligning Science, Practice, and Policy to Advance Health Equity

Given the large size and rural nature of New Mexico, and the severe shortage of health care and social service providers of all kinds, these difficulties are not unique to CYSHCN. However, given the greater use of health care and greater difficulty in accessing care by CYSHCN, these issues are particularly acute for children with special health care needs.

How can we reduce the number of CYSHCN who have problems getting referrals to specialists? How can we increase holistic care coordination for this population? Models that have been used with success in other states use a variety of technology-based services, including telemedicine - healthcare delivery that employs telecommunications and computer technology as a substitute for face-to-face contact between provider and patient⁵ - as well structured videoconferencing for case analysis such as Project ECHO (Extension for Community Healthcare Outcomes) to accomplish this.

Given the Cultural and Linguistic Diversity of CYSHCN in the State, an Assessment is Needed of the Adequacy of the Cultural and Linguistic Appropriateness of Services

New Mexican children with special health care needs reflect the rich racial and ethnic diversity of the state as a whole. Too little is known about the extent to which programs and services - including health care - offered to these children and their families are culturally and linguistically appropriate. Interpretation and translation services are important factors, as is receiving information in their preferred language. Finally, we need to assess the extent to which providers of health and other services understand the role of culture and language in providing effective services. Family culture in a state with many rural and frontier communities is an important consideration in the provision of services.

References

1. Braveman, P., Arkin, E., Orleans, T., Proctor, D., & Plough, A. What is health equity? And what difference does a definition make? Princeton, New Jersey, USA: Robert Wood Johnson Foundation, 2017.
2. Howard, S., Dryden, J., & Johnson, B. (1999). Childhood resilience: Review and critique of literature. *Oxford review of education*, 25(3), 307-323.
3. West, D. J., & Farrington, D. P. (1973). Who becomes delinquent? Second report of the Cambridge Study in Delinquent Development.
4. National Academies of Sciences, Engineering, and Medicine 2019. *Vibrant and Healthy Kids: Aligning Science, Practice, and Policy to Advance Health Equity*. Washington, DC: The National Academies Press. <https://doi.org/10.17226/25466>.
5. Bashshur, R. L. (1995). On the definition and evaluation of telemedicine. *Telemedicine Journal*, 1(1), 19-30.

Mission Statements



The mission of the New Mexico Department of Health is to promote health and wellness, improve health outcomes, and assure safety net services for all people in New Mexico.



The mission of the Center for Development and Disability is to advance exemplary services, research, education and policies to support the well being of all New Mexicans.

For more information contact Dr. Anthony Cahill
acahill@salud.unm.edu

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