Children and Youth with Special Health Care Needs (CYSHCN)

FY26 MCH Title V Needs Assessment

IOWA Health and Human Services

Percent of children with and without special health care needs, ages 0 through 17, who have a medical home (MH)

Why – A medical home is a way of providing complete primary care that builds strong relationships between patients, doctors, medical staff, and families. It goes beyond just the doctor's office and includes things like communication, family support, and access to specialist care and educational services. Having a Medical Home is associated with improved health outcomes for the population, increased satisfaction for children and families, and decreased cost of care.1

What – In Iowa, most Children and Youth with Special Health Care Needs (CYSHCN) had a personal doctor or nurse (84%). Iowa ranks 7th among the states on this measure. But having a medical home is more than just having a personal doctor or nurse. It also includes things like help coordinating care, referrals to specialty services, and care that focuses on the family's needs. For Children and Youth with Special Health Care Needs, fewer than half (47%) have a medical home. While Children and Youth with Special Health Care Needs are more likely to have a personal doctor or nurse and a usual source for care when they are sick, they are less likely to have needed access to referrals, care coordination, and family-centered care (CHART 1). Iowa ranks 45th among states for this measure.

Health Disparity –Those in more suburban areas consistently report better access to medical home approaches to care than those in central cities or more rural areas (CHART 2).

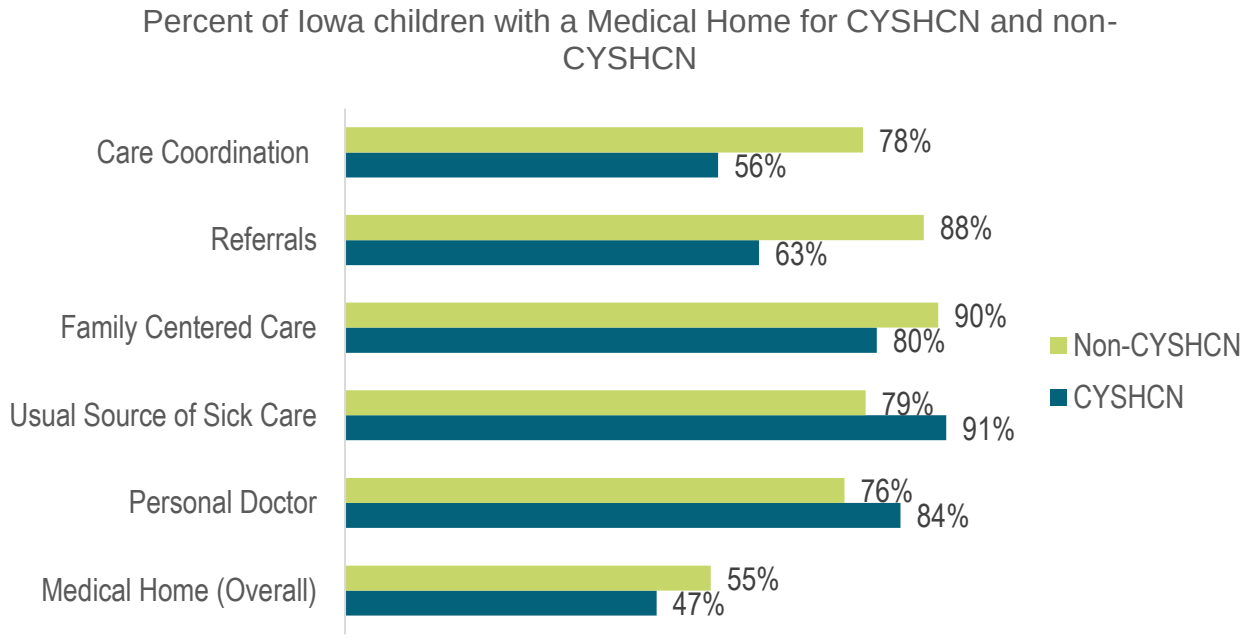

CHART 1. Source: National Survey of Children's Health (NSCH) 2021-2022

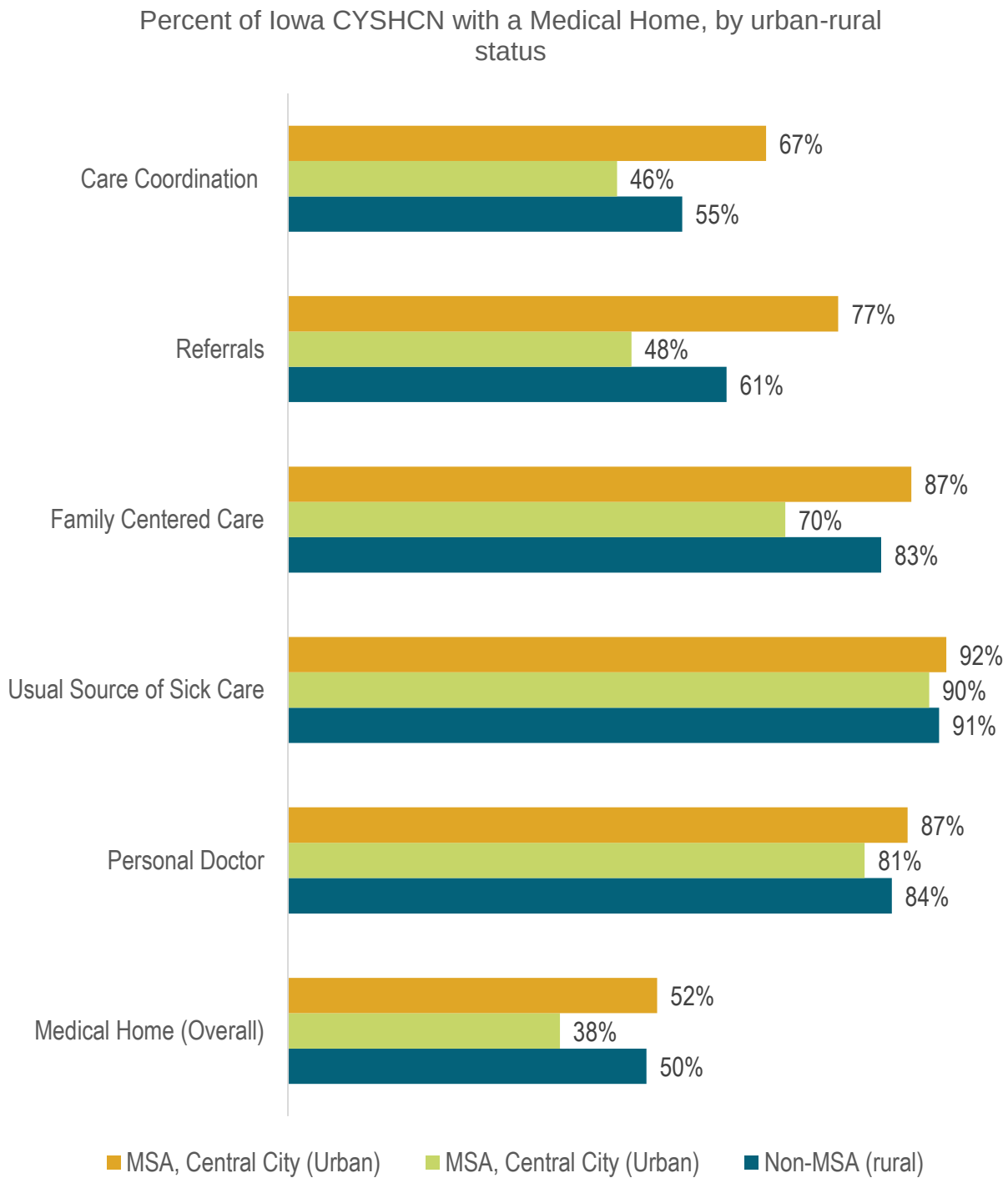

CHART 2. Source: National Survey of Children's Health (NSCH) 2021-2022

Adolescents who received services to prepare for the transition to adult health care:

Why - When children are young, parents handle medical tasks like scheduling appointments, filling out forms, and managing medications. As children grow up, they take on more of these responsibilities. Reaching life goals means both youth and their parents need to be prepared and knowledgeable. Families with children who have special health care needs often need extra help when moving to adult health care services.

What – 40% of youth with special health care needs (YSHCN) ages 12-17 received services necessary to make transitions to adult health care during their last medical care visit.

Health Disparity – YSHCN in more rural (non-MSA) areas were most likely to have transition services reported by parents or caregivers, and those in more suburban areas were least likely (CHART 3).

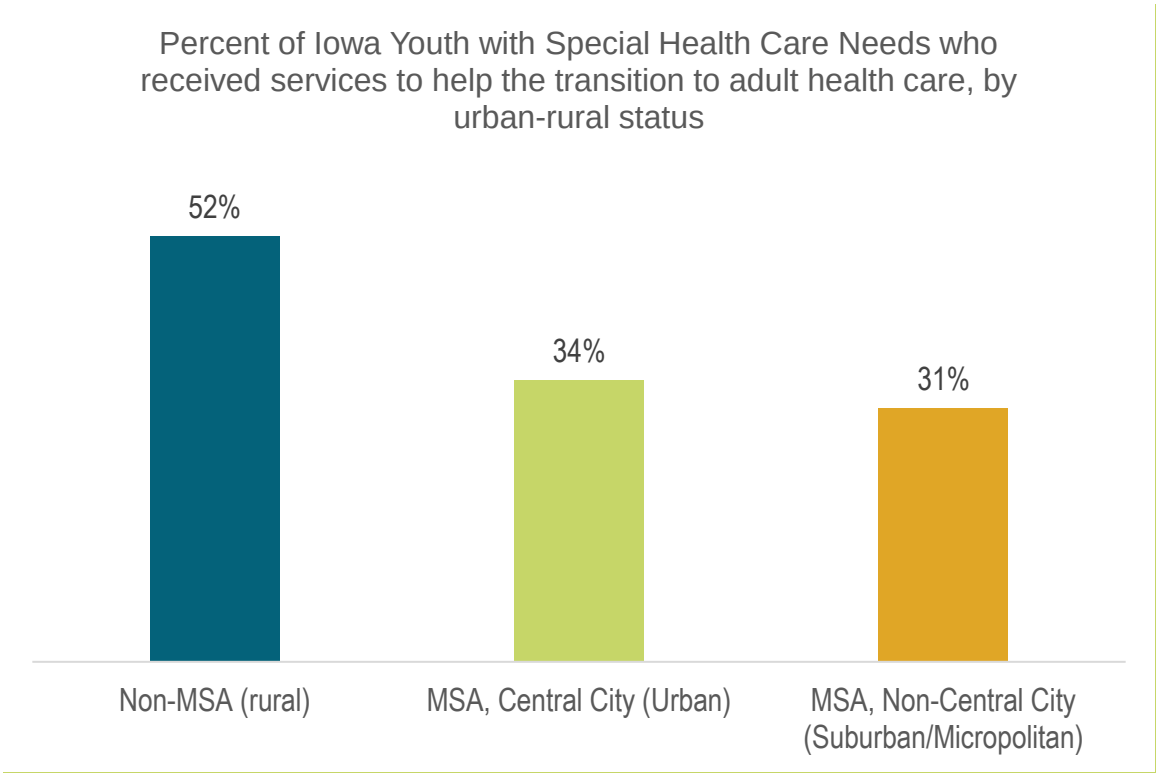

CHART 3. Source: National Survey of Children's Health (NSCH) 2021-2022

Percent of adolescents, ages 12 through 17, who are bullied or who bully others (BLY)

Why – Bullying is when a child or group repeatedly targets another child with aggressive behavior. This can happen in different ways: physical (hitting or tripping), verbal (name-calling or taunting), or social (excluding someone on purpose or spreading rumors). Bullying can also happen online.2 Children who bully often have behavioral issues and school challenges. Children who are bullied report low self-esteem, difficulties in school, and mental health problems.

What – In the 2021-2022 period, 41.8% of all children in Iowa were reported to have been bullied, placing the state 6th highest among US states. For CYSHCN, the rate was even higher at 64.1%, ranking Iowa 3rd. Additionally, 17.2% of children were reported to bully others, with this figure rising to 25.5% among those with special health care needs.

Health Disparity – Bullying incidents were more frequently reported for adolescents who have adverse childhood experiences. Specifically, 65.3% of youth who had two or more adverse childhood experiences were reported as being bullied, compared to 37.2% of those with one and 30.8% with none. (figure). Similarly, youth with more adverse childhood experiences were more likely to be reported as bullies, with 29.4% with two or more adverse childhood experiences, 16.5% with one, and 10.1% with none (chart 4).

Adverse childhood experiences, often called ACEs, are negative events that happen in a child's life before they turn 18. These can include things like abuse, neglect, witnessing violence, or having a family member with mental illness or substance abuse problems. These experiences can have a big impact on a child's mental and physical health, even into adulthood.3

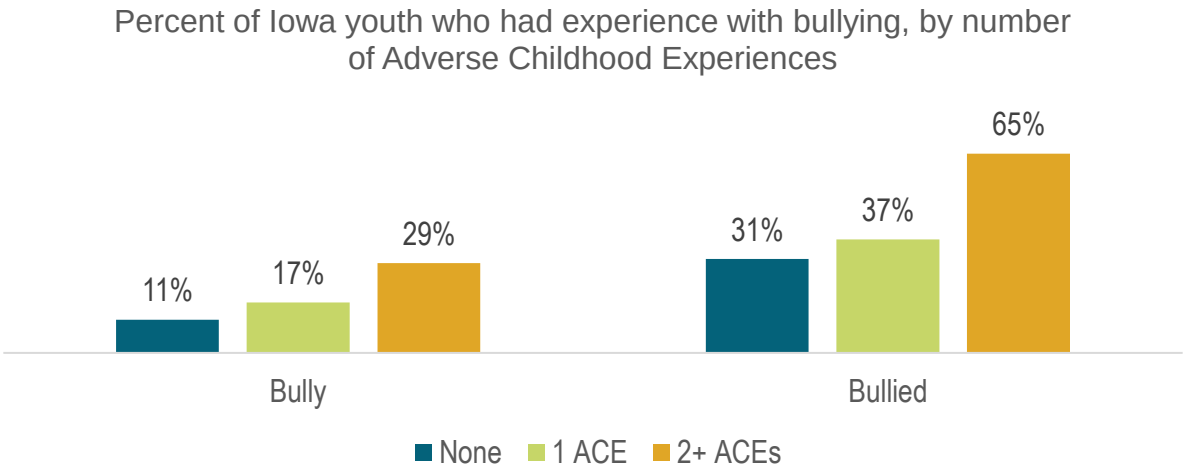

CHART 4. Source: National Survey of Children's Health (NSCH) 2021-2022

Emerging Issue

Support for Families of Children and Youth with Special Health Care Needs (SPM)

Why – Parents/caregivers who feel supported, confident, and competent are better able to nurture their child's emotional, physical, and developmental growth. Connecting families to training and support helps empower them to manage the additional parenting responsibilities that are often associated with having a child with a special health care need. This is especially relevant to parents/caregivers of children with complex health needs.

What – Children with complex health needs are more likely to have parents who reported challenges in parenting (23.1%) when compared to children without special health care needs (1.3%) (CHART 5). They are also less likely to report that they are handling the day-to-day demands of parenthood "very well" (40.2% vs 57.9%). Furthermore, children with complex health needs were significantly more likely to have mothers who reported their mental health status as fair or poor (14.2% vs 6.1%).

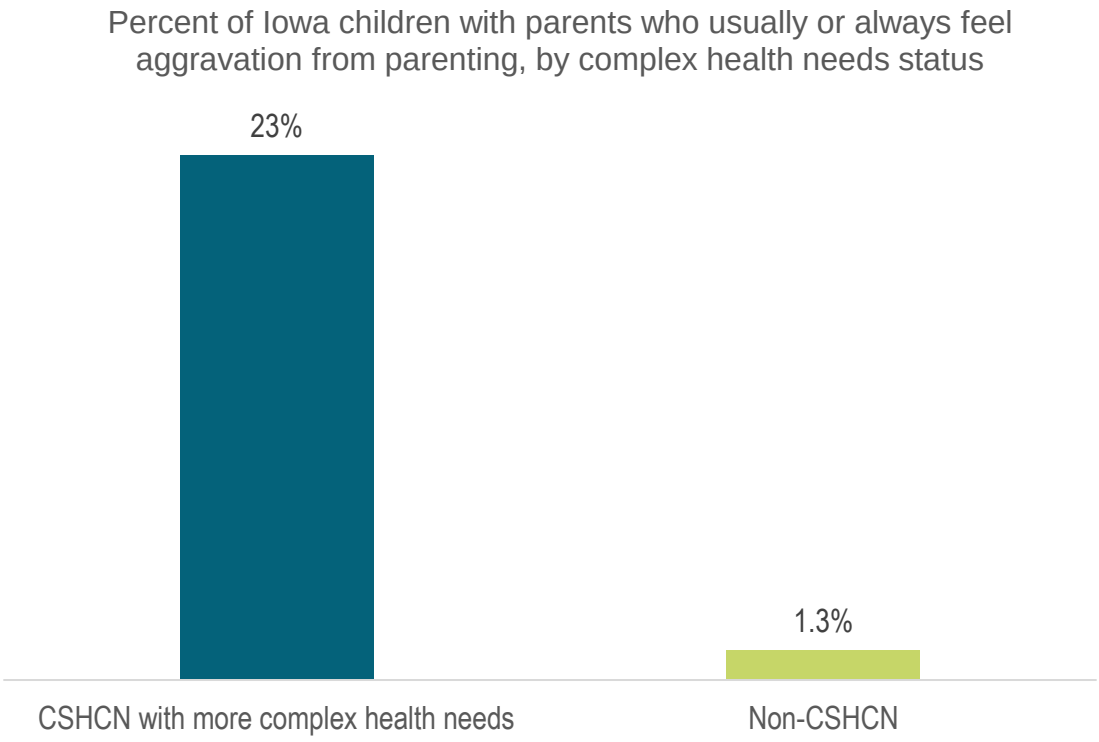

CHART 5. Source: National Survey of Children's Health (NSCH) 2021-2022

[1] American Academy of Pediatrics National Resource Center for Patient/Family-Centered Medical Home https://www.aap.org/en/practice-management/medical-home/

[2] Gladden, R.M., Vivolo-Kantor, A.M., Hamburger, M.E., & Lumpkin, C.D. Bullying Surveillance Among Youths: Uniform Definitions for Public Health and Recommended Data Elements, Version 1.0. Atlanta, GA; National Center for Injury Prevention and Control, Centers for Disease Control and Prevention and U.S. Department of Education; 2014. https://www.cdc.gov/youth-violence/media/pdf/bullying-definitions-final-a.pdf

[3] Centers for Disease Control and Prevention, Adverse Childhood Experiences https://www.cdc.gov/aces/about/index.html