Increasing Access to Early Screening and Identification for CYSHCN

Problem Statement

In the US, 1 in 6 children aged 3-17 have a developmental disability.[1] Providers across the US have not yet met the national guidelines for all children to receive timely developmental screenings and specific autism spectrum disorder (ASD) screenings.[2]

According to the 2022 National Survey of Children's Health (NSCH), only 31.6% of Nebraska children aged 9-35 months received a developmental screening, compared to 34.4% nationally.[3] There is a steady increase nationally since 2002 in children diagnosed with ASD[4]; however, only 1.8% of Nebraska children aged 3-17 were diagnosed with ASD compared to 3.6% nationally.[3] Developmental screenings are recommended to identify developmental delays early in order to receive prompt intervention services to maximize key periods of brain development. This improves a child's ability to learn, develop skills, and adapt to change as they age. Early screening and identification can prevent long-term health problems if there is appropriate follow-up and connection to treatment.[2]

Criterion 1: Disproportionate Outcomes Exist Among Subgroups of the Population

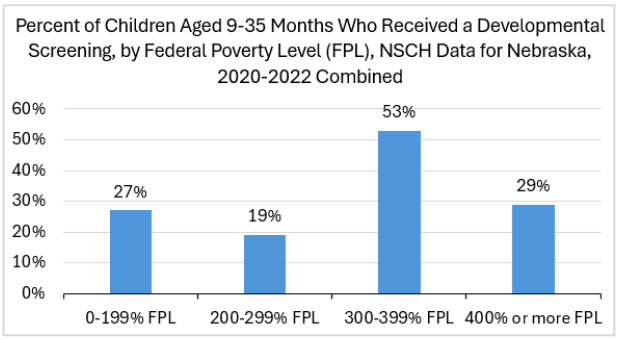

Figure 1. Source: National Survey of Children's Health[3]

The 2020-2022 NSCH survey data revealed that receipt of developmental screening for children aged 9-35 months varied by poverty level (Figure 1).[3] That survey data also revealed 26% of children aged 9-35 months without a medical home received a developmental screen compared to 34% of children the same age with a medical home.[3] Data also showed that the prevalence of ASD diagnoses remained steady from 2018-2022, and, in 2022, 3.5% of males and 0.2% of females aged 3-17 years in Nebraska had been diagnosed with ASD.[3]

Additionally, Nebraska data showed that developmental screening for autism was administered by 80% of pediatric providers and only 30% of family practice primary care providers, with no difference in rural or urban areas.[5] However, according to 2019 data, the majority of primary care providers across Nebraska are family medicine/general practice (45.1 per 100,000 population) compared to pediatricians (15.9 per 100,000 population) (see Figure 2 and 3 below).[6] Most counties in Nebraska do not have a pediatrician; however, family practice/general practice physicians are available in most counties. To improve developmental screening, we need to increase education on how to screen for ASD at family practice locations to have the biggest impact.

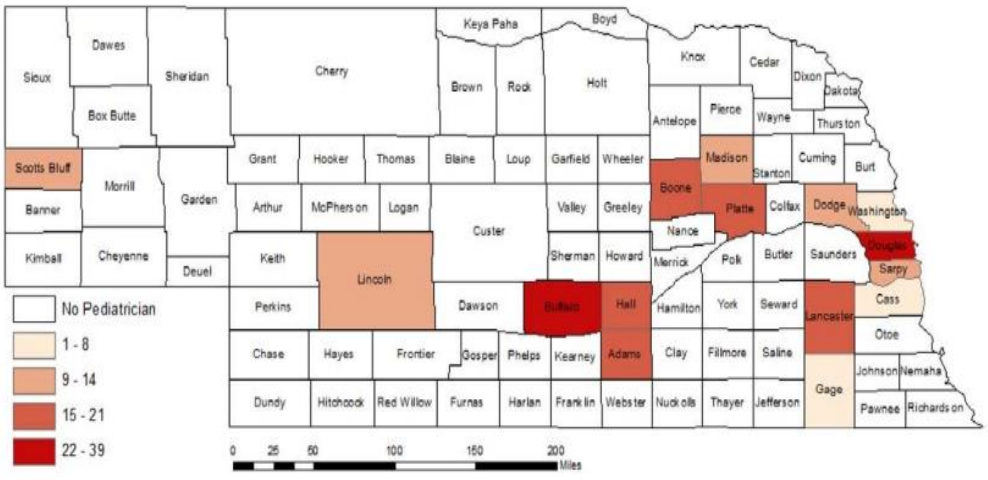

Figure 2. Number of active pediatric primary care physicians per 100,000 population by county, Nebraska[6]

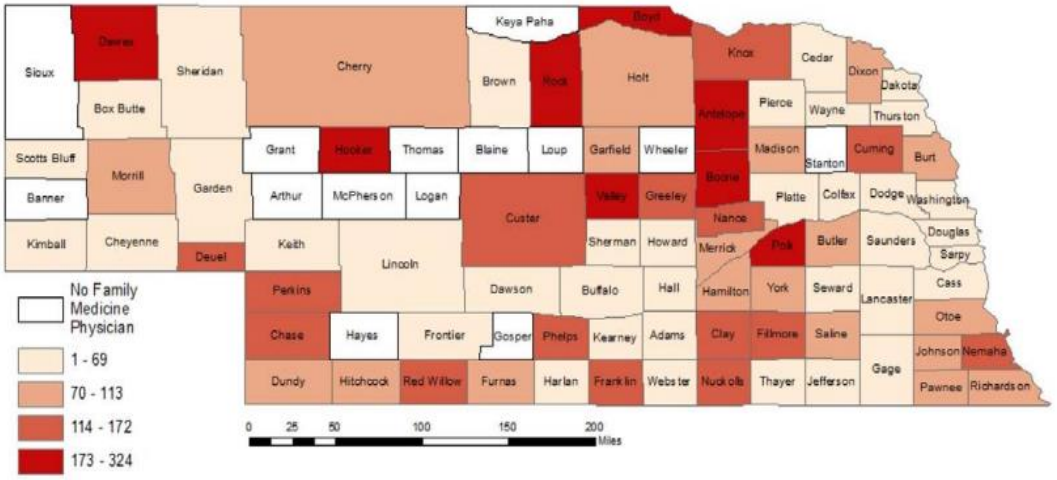

Figure 3. Number of active family medicine physicians per 100,000 population by county, Nebraska[6]

Criterion 2: Strategies Exist to Address the Problem/An Effective Intervention is Available

The American Academy of Pediatrics recommends developmental screenings for all children at 9-, 18-, and 30-months of age with additional screening for ASD at 18- and 24-months.[2] These guidelines were established in January of 2020 and reaffirmed in April 2024.[2] However, pediatricians have reported difficulties meeting these standards due to time limitations and inadequate payment.[2] Nebraska can capitalize on interdisciplinary collaborations and community resources to leverage completion of developmental screenings from multiple entities in Nebraska. This will ensure identification of those in need in a timely manner to maximize treatment for optimal outcomes in a more cost-effective way.

To address the implementation of developmental screenings and access to identification, there are 9 evidence-based/informed strategies documented in the Maternal Child Health Evidence Accelerator from MCHbest and 25 field-based practices from Innovation Hub. These strategies can be initiated alone, combined with other strategies, or modified to meet community need.[7] The following effective strategies would have a significant impact on access to early screening and identification in Nebraska:

Scientifically rigorous evidence[7]:

- **Medical Home:** Patient centered medical homes (PCMH) provide evidenced-based, comprehensive primary care by primary care providers and extended teams coordinating care across the health care system, working with patients to address all their health care needs.

Moderate evidence[7]:

- **Home Visiting Programs:** Providers conducting home visiting sessions to encourage parents to complete developmental screening. Nebraska has multiple home visiting programs, such as Nebraska-Maternal Infant Early Childhood Home Visiting (N-MIECHV), Sixpence, Early Head Start, and Buffett Early Childhood institute.
- **Provider Training:** Professional post-secondary training on developmental screening.
- **Implementation of Quality Standards:** Groups, such as local public health agencies, that oversee a statewide learning collaborative for quality improvement components.
- **Quality Improvement Programs in Health Care Settings:** Groups, such as local public health agencies, that support a practice-based learning collaborative for primary care practices.

- **Telephone-Based Developmental Screening (National, State, or Centralized):** Developmental screening conducted via the phone through a national, state, or centralized organization.
- **Enhanced Medical Records (EMR):** EMRs that allow collection of patient-recorded outcome measures through a tablet or portal pre-visit.

Field-based practices that are identified as **best** practices[7]:

- **Community Health Workers (CHW) Program**: A CHW is a trusted member of the community they serve. They build relationships with people in the community and help connect them to care, support increased health knowledge, and advance their self-sufficiency.[8]

Nebraska supports the expansion of the PCMH and can capitalize on new CHW programs to connect to extensive resources across the state, such as Early Development Network (EDN), home-visiting programs, and online/telephone program, to ensure completion and understanding of developmental screenings.

Criterion 3: Capacity to Address the Problem

All states are required to provide Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services to children under 21 enrolled in Medicaid to correct and ameliorate health conditions.[9] Nebraska has also demonstrated a variety of public and private partners, institutions, and service providers that ensure the state has the capacity for change and support of developmental screening and assessments. These include:

- **Medical Home:** Nebraska DHHS requires their managed care organizations to support PCMH and work to have all its primary care providers recognized as a PCMH.
- **Help Me Grow Nebraska:** Provides free online developmental screening to families.
- **Home Visiting Programs:** Sixpence, N-MIECHV, and Nebraska EDN provide home visiting programs in Nebraska. EDN is a state Title V project, required under the federal Individuals with Disabilities Education Act and Nebraska's Rule 52, that provides free early intervention in-home services to families with children birth-3 years with developmental delays and/or special healthcare needs. EDN includes 28 Planning Region Teams that serve the entire state.
- **Nebraska Head Start Association:** Child screening and assessment and center-based education.
- **Tracking Infant Progress Statewide (TIPS):** A collaborative project between the Munroe-Meyer Institute (MMI), EDN, and local health organizations across Nebraska to provide specialized developmental follow-up for children who were in a neonatal intensive care unit (NICU) and are at a higher risk for developmental delays and connect them to local early intervention programs.
- **CDC's '*Learn the Signs. Act Early*'**: Produced the "Learn the Signs. Act Early" program that aims to improve early identification of children with ASD and developmental disabilities so that children and families can get the services and support they need. The UNMC/MMI currently hosts the current CDC state ambassador.
- **MMI and University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDD):** Serves as a bridge between the universities/medical centers to provide supports for families and represent a national resource for the promotion of independence, self-determination, productivity, and integration of individuals with developmental disabilities.
- **EarliPoint Evaluation for ASD:** An eyegaze assessment device at MMI for children between 16-30 months that provides an ASD assessment in half the time it currently takes to complete an ASD evaluation. MMI is currently involved in a clinical trial to extend the age upward.[10]

- **CHW Programs:** Family Care Enhancement Project, CHW Training and Certification Program at UNMC College of Public Health, CHW Training Apprenticeship & Placement Program at Creighton University, and the Nebraska Association of Local Health Directors have all grown capacity at the local level for CHW support.

Connecting these existing resources to families through their medical home/primary care will allow children to receive the developmental screening and identification they need. Nebraska needs better coordination and utilization of services for children across the entire state.

Criterion 4: Problem is Worse than the Benchmark or Worsening

Children in Nebraska, aged 9-35 months, who received a developmental screening in the past year was consistently lower than the national average for 2018-2022 (Figure 4, 2022 data).[3]

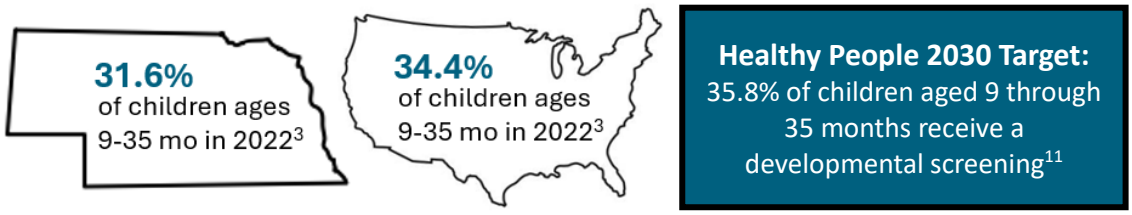

Figure 4. Nebraska and US children aged 9-35 months who received a developmental screening, 2022.[3]

In 2022, 3.6% of children, aged 3-17, were diagnosed with ASD nationally, compared to only 1.8% in Nebraska.[3] The percentage of Nebraskan children diagnosed with ASD remained stable from 2018-2022 and lower than the US average in 2018 and 2020-2022.[3]

Criterion 5: Community Readiness to Address the Problem

Health departments across Nebraska have increased MCH services in the past 5 years. Many have now included home visits as a part of their services to address family needs. In 2023-2024, the N-MIECHV program reported that 75% of children had a timely screen for developmental delays. That same year, the program reported that 100% of children with positive screens for developmental delays received one or more service contacts.[12] Hundreds of children are reported to be on ASD diagnostic waiting lists in Nebraska and MMI has invested in tools to reduce the wait to receive a diagnosis to receive treatment earlier.[9] The current resources are also already in place to build capacity at the local health department level. The Nebraska community is ready to address this problem.

If this issue is selected as one of the Title V MCH priority needs in 2025, what do you expect this issue to look like five years from now? What kind of progress can you expect for the next five years?

- Universal developmental screening provided by a variety of providers in connection with primary care offices (family practice & pediatricians) and PCMH across the state.
- Developmental screenings completed equivalently across all demographics of children.
- Technology for families to fill out developmental screening tools via a tablet, telephone, QR code, app, etc., with results uploaded into the patient's electronic health records.
- Supported referrals/follow-up to and from EDN services and training on EPSDT to families and clinicians.
- The percentage of Nebraska children with an ASD diagnosis will match national data.

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