

## National Center for a System of Services for Children and Youth with Special Health Care Needs National Survey of Children's Health Indicators by Blueprint Critical Area

**Introduction:** Through a collaboration with the Altarum Institute, the [National Center for a System of Services for CYSHCN](#) identified National Survey of Children's Health (NSCH) indicators that may align with the four critical areas of the [Blueprint for Change](#).

**How to Use this Resource:** The table below can help state/jurisdiction Title V programs identify key data points within the NSCH that align with critical areas of the Blueprint for Change. States/jurisdictions can use this information to monitor their progress across the four Blueprint critical areas during their 5-year and ongoing needs assessment activities. This tool can help states/jurisdictions to better understand how their work aligns with and advances the Blueprint for Change.

### Approach:

- Sections from the [2021 NSCH Guide to Topics and Questions](#) asked were used as a reference to identify key NSCH indicators.
- Indicators were aligned with content from the Blueprint for Change *Pediatrics* supplement articles.
- Indicators were reviewed by subject matter experts including lead authors of the Blueprint for Change, the National Center Consortium partners (American Academy of Pediatrics, Boston University, Got Transition, Family Voices), MCHB/HRSA, and state Title V CYSHCN programs.

The indicators and their alignment to Blueprint critical areas are informed by the above, and we acknowledge that state/jurisdiction Title V programs and their partners may see relationships differently since the four critical areas of the Blueprint for Change intersect. For example, many financing indicators also relate to access to services (example: children who were not able to receive needed health care due to cost relates to both finance, access, and equity). Since the Blueprint for Change framework is broad, there is room for interpretation of where each indicator may intersect with the Blueprint critical areas.

For technical assistance and support, contact the National Center at: [Blueprint4CYSHCN@aap.org](mailto:Blueprint4CYSHCN@aap.org).

For more information about the National Survey of Children's Health, visit the [Data Resource Center for Child and Adolescent Health](#).

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Blueprint Critical Areas	NSCH Indicators (Variable Code)
<b>Health Equity</b>	<ul style="list-style-type: none"> <li>• Income based on federal poverty level status (povlev4_2021)</li> <li>• Child's race (SC_RACER)</li> <li>• Hispanic, Latino or Spanish origin (C#_HISPANIC_R)</li> <li>• How well does this child speak English? (C#_ENGLISH)</li> <li>• Treated or judged unfairly because of their race or ethnic group (ACE10)</li> <li>• Treated or judged unfairly because of their sexual orientation or gender identity (ACE12)</li> <li>• ^Treated or judged unfairly because of a health condition or disability (ACE11)</li> <li>• Qualifying reason on the CSHCN Screener: Prescription medication criteria (rxmeds_2021); For elevated use of services criteria (serve_2021); Functional limitations criteria (func_2021); Specialized therapy criteria (therapy_2021); Ongoing emotional, developmental or behavioral criteria for which treatment or counseling is needed (mhealth_2021)</li> <li>• NOM-17.2: Percent of children with special health care needs (CSHCN), ages 0-17, who receive care in a well-functioning system (nom17_2sysCSHCN_2021)</li> <li>• NPM-11 Percent of children with special health care needs, ages 0 through 17, who have a medical home</li> <li>• NPM 12 Transition to adult health care</li> <li>• Family feels like a partner in your child's care (K5Q44)</li> <li>• Child needed healthcare but it was not received (K4Q27)</li> <li>• Complexity of health care needs (CSHCNComplex_2021)</li> </ul>
<b>Family and Child Well-Being and Quality of Life</b>	<p>Child:</p> <ul style="list-style-type: none"> <li>• Flourishing for young children, age 6 months-5 years (flrishoto5_2021)</li> <li>• Flourishing for children and adolescents, age 6-17 years (flrish6to17_2021)</li> <li>• Difficulties making or keeping friends, age 6-17 years (MakeFriend_2021)</li> <li>• Children who are bullied, picked on, or excluded by other children during the past 12 months, age 6-17 years (bullied_2021)</li> <li>• Missed school days, age 6-17 years (SchlMiss_2021)</li> <li>• Children participate in organized activities outside school, age 6-17 years (AftSchAct_2021)</li> </ul> <p>Family:</p> <ul style="list-style-type: none"> <li>• Family flourishing composite measure (FamResilience_2021)</li> <li>• Parents who felt stress from parenting during the past month (ParAggrav_2021)</li> <li>• Children living with parents who have someone that they could turn to for day-to-day emotional support with parenting or raising children (EmSupport_2021)</li> <li>• Coping with day-to-day demands of raising children (ParCoping_2021)</li> </ul>

Neighborhood:

- Children who live in a supportive neighborhood (NbhdSupp\_2021)
- Children live in safe neighborhoods (NbhdSafe\_2021)
- Safe schools, age 6-17 years (SchlSafe\_2021)
- Children who live in neighborhoods with libraries, parks, sidewalks, or recreation centers (library\_2021; park\_2021; RecCentr\_2021; SideWlks\_2021)

Forgone Health Care:

- There were problems getting an appointment when this child needed one (APPOINTMENT)
- There were problems with getting transportation or child care (TRANSPORTCC)

Family-Centered Care:

- DURING THE PAST 12 MONTHS, how often did this child's doctors or other health care providers:
  - Spend enough time with this child? (K5Q40)
  - Listen carefully to you? (K5Q41)
  - Show sensitivity to your family's values and customs? (K5Q42)
  - Provide the specific information you needed concerning this child? (K5Q43)
  - Help you feel like a partner in this child's care? (K5Q44)

Shared Decision Making:

- Make it easy for you to raise concerns or disagree with recommendations for the child's health care? (RAISECONC)
- Work with you to decide together which health care and treatment choices would be best for this child? (BESTFORCHILD)

Transition to Adult Health Care:

- Have this child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs? (WRITEPLAN)
- If yes, do you and this child have access to this plan of care? (RECEIVECOPY)

Providing for this Child's Health:

- DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or health care bills? (K3Q25)
- DURING THE PAST 12 MONTHS, have you or other family members:
  - Left a job or taken a leave of absence because of this child's health or health conditions? (STOPWORK)
  - Cut down on the hours you work because of this child's health or health conditions? (CUTHOURS)
  - Avoided changing jobs because of concerns about maintaining health insurance for this child? (AVOIDCHG)
- IN AN AVERAGE WEEK, how many hours do you or other family members spend providing health care at home for this child?

	<p>(ATHOMEHC)</p> <ul style="list-style-type: none"> <li>• IN AN AVERAGE WEEK, how many hours do you or other family members spend arranging or coordinating health or medical care for this child, such as making appointments or locating services? (ARRANGEHC)</li> </ul> <p>About You and This Child:</p> <ul style="list-style-type: none"> <li>• DURING THE PAST 12 MONTHS, did you or anyone in the family have to quit a job, not take a job, or greatly change your job because of problems with child care for this child? (K6Q27)</li> </ul> <p>The Child's Schooling and Activities:</p> <ul style="list-style-type: none"> <li>• DURING THE PAST 12 MONTHS, how often did you attend events or activities that this child participated in? (K7Q33)</li> </ul> <p>About your Family and Household:</p> <ul style="list-style-type: none"> <li>• Which of these statements best describes your household's ability to afford the food you need DURING THE PAST 12 MONTHS? (FOODSIT)</li> </ul> <p>Child's Caregiver:</p> <ul style="list-style-type: none"> <li>• In general, how is your/this caregiver's physical health? (A1_PHYSHEALTH) (A2_PHYSHEALTH)</li> <li>• In general, how is your/this caregiver's mental or emotional health? (A1_MENTHEALTH) (A2_MENTHEALTH)</li> </ul>
<p><b>Access to Services and Supports</b></p>	<ul style="list-style-type: none"> <li>• NPM-6: Percent of children, ages 9-35 months, who received a developmental screening using a parent-completed screening tool in the past year (npm6Dsc_2021)</li> <li>• NPM-10: Percent of adolescents, age 12-17 years, with a preventive medical visit in the past year (npm10PrVi_2021)</li> <li>• NPM 13 Preventive dental visit</li> <li>• NPM-11: Percent of children with special health care needs, ages 0-17, who have a medical home (npm11MHCSHCN_2021) <ul style="list-style-type: none"> <li>○ Personal doctor or nurse (Indicator 4.12a: PerDrNs_2021)</li> <li>○ Usual source for sick care (Indicator 4.12b: UsualSck_2021)</li> <li>○ Family-centered care (Indicator 4.12c: FamCent_2021)</li> <li>○ Problems getting needed referrals (Indicator 4.12d: NoRefPrb_2021)</li> <li>○ Effective Care Coordination when needed (Indicator 4.12e: CareCoor_2021)</li> </ul> </li> <li>• NPM-12: Percent of adolescents with special health care needs, ages 12-17, who received services necessary to make transitions to adult health care (npm12TransCSHCN_2021) <ul style="list-style-type: none"> <li>○ If yes, have they talked with you about when this child will need to see doctors or other health care providers who treat adults? (TREATADULT)</li> <li>○ Has this child's doctor or other health care provider actively worked with this child to Understand the changes in health care that happen at age 18? (CHANGEAGE)</li> </ul> </li> <li>• NOM-25: Percent of children, ages 0-17, who were not able to obtain needed health care in the last year (nom25ForgoneHC_2021)</li> </ul>

	<ul style="list-style-type: none"> <li>• Children who were not able to receive needed: Medical care during the past 12 months (ForegoneMed_2021); Dental care during the past 12 months (ForegoneDent_2021); Vision care during the past 12 months (ForegoneVis_2021); Hearing care during the past 12 months (Foregone_Hear_2021); Mental health services during the past 12 months, age 3-17 years (ForegoneMH_2021)</li> <li>• Children who were not able to receive needed health care because: Child was not eligible (ineligible_2021); The service this child needed was not available in their area (unavailable_2021; There were problems getting an appointment (appointment_2021); There were problems with getting transportation or child care (transport_2021); The office was not open when the child needed care (NotOpen_2021)</li> <li>• Family often frustrated in efforts to get services for their children during the past 12 months (frustrated_2021)</li> <li>• Number of hours spent coordinating health care for child in an average week (TimeCoord_2021)</li> <li>• Family needed extra help to coordinate child's health care (ExtraHelp_2021)</li> <li>• Family got needed help with coordinating child's health care in the past 12 months (HelpCoord_2021)</li> <li>• Children whose families are partners in shared decision-making for their optimal health (ShareDec_2021)</li> <li>• Health care provider communicated with child's school, child care provider, or special education program (OtherComm_2021)</li> <li>• Satisfaction with communication among child's doctors and school, child care provider, or special education program (SatOthComm_2021)</li> <li>• Satisfaction with communication among child's doctor and other health care providers (DrCommR_2021)</li> <li>• DURING THE PAST 12 MONTHS, did this child need a referral to see any doctors or receive any services? (K5Q10); How difficult was it to get referrals? (K5Q11)</li> </ul>
<p><b>Financing of Services</b></p>	<ul style="list-style-type: none"> <li>• NPM-15: Percent of children, ages 0-17, who are continuously and adequately insured (npm15AdIns_2021)</li> <li>• Family had problems paying for children's medical or health care bills during the past 12 months (MedBills_2021)</li> <li>• Children who were not able to receive needed health care due to cost (CostIssue_2021)</li> <li>• Current insurance benefits meets child's health needs (benefits_2021)</li> <li>• Current insurance coverage allows child to see needed providers (allows_2021)</li> <li>• Current insurance out-of-pocket costs are reasonable (expense_2021)</li> <li>• Thinking specifically about this child's mental or behavioral health needs, how often does this child's health insurance offer benefits or cover services that meet these needs? (MENBEVCOV)</li> <li>• 3.5 Adequacy of insurance coverage for mental health care, 3-17 years</li> <li>• 3.4 Adequacy of current insurance</li> <li>• 3.3 Type of health insurance</li> <li>• 3.2 Consistency of insurance coverage <ul style="list-style-type: none"> <li>○ Health insurance coverage – Past 12 months (INSGAP) or Health insurance type (instype_2021)</li> </ul> </li> <li>• 3.1 Current health insurance status <ul style="list-style-type: none"> <li>○ DURING THE PAST 12 MONTHS, was there any time when this child needed health care but it was not received? (K4Q27)</li> </ul> </li> <li>• 6.27 Received food or cash assistance</li> </ul>

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|  | <ul style="list-style-type: none"><li>• 6.28 Child receives SSI</li><li>• 6.29 Not able to pay rent or mortgage</li><li>• 6.30 Caregiver stress about being evicted or removed from house</li><li>• 6.32 Child ever experienced homelessness</li></ul> |
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