

## Calculating Children and Youth with Special Health Care Needs (CYSHCN) Prevalence: A Deep Dive

The purpose of this one-pager is to summarize key resources and information about proposed changes to CYSHCN prevalence calculations.

### Why Does Current CYSHCN Prevalence Calculation Need to be Re-Examined?

- Title V programs have inquired about how best to calculate children who are in the “at risk” category for acquiring special health care needs.
- Prior work has documented the potential for both over- and under- identification of CYSHCN among specific subgroups, including those with minoritized identities.
- Analysis of current National Survey of Children’s Health (NSCH) data reveal that there are children who do not qualify as CYSHCN based on the CYSHCN screener but still report as having a chronic condition and a functional limitation.
- A more accurate calculation of CYSHCN prevalence can support appropriate allocation of resources and support to advance the system of services for CYSHCN in a way that is meaningful to families/caregivers.

### What is the Proposed Change to CYSHCN Prevalence Calculation?

- Currently, prevalence of CYSHCN is calculated based on responses to the CYSHCN screener which is part of the NSCH. More information about the [CYSHCN screener is available here](#).
- MCHB proposed to expand the calculation of CYSHCN in the NSCH by including all children who screen positive on the CYSHCN screener as well as children whose caregivers report both a condition and a limitation.
- This proposal would increase CYSHCN prevalence from 19% to 25% of all children.

### What Does this Mean for Title V CYSHCN Programs?

- Title V CYSHCN programs are already caring for these children throughout their programming.
- This new count presents a more accurate picture of population served through Title V CYSHCN programs and may help programs with data reporting and appropriate allocation of resources.
- This new count may also help Title V CYSHCN programs gain a better understanding of which CYSHCN subpopulations may have been undercounted in the past, and where to better focus their programming efforts.

### Resources

- [Blueprint National Center Virtual Cafés](#)
- [Data Resource Center for Child and Adolescent Health](#)

The National Center for a System of Services for CYSHCN is available to provide individualized support and technical assistance to Title V CYSHCN who have specific questions about this content. Contact [Blueprint4CYSHCN@aap.org](mailto:Blueprint4CYSHCN@aap.org) with questions. Visit [our Web site](#) for more resources.

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