

# Methodologic Considerations for Transition Research Using the National Survey of Children with Special Health Care Needs: A Systematic Review of the Literature

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## ABSTRACT

The purpose of this review was to describe methodologic considerations in using the National Survey of Children With Special Health Care Needs (NS-CSHCN) for transition research in terms of variable inclusion and definition of transition outcomes and to provide suggestions for using NS-CSHCN for transition research. A systematic review was conducted.

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Inclusion criteria included use of NS-CSHCN data and transition as an outcome variable. Fourteen studies were included. Ten (71%) studies evaluated a sample of all CSHCN. Ten (71%) articles used all four variables recommended by the Maternal and Child Health Bureau core outcome on transition. Other variables included patient-centered medical home. The NS-CSHCN provides a rich dataset that can be used in transition research addressing transition preparation from the parent perspective. Using the NS-CSHCN, we recommend analyzing all variables related to the Maternal and Child Health Bureau core outcome for transition, variables related to patient-centered medical home, and further analysis of specific health conditions. *J Pediatr Health Care.* (2018) ■■■, ■■■-■■■.

## KEY WORDS

Children with special health care needs, national survey of children with special health care needs, secondary data analysis, transition

Advances in care have improved the survival of children with special health care needs (CSHCN). It is now estimated that 20% of youth in the United States have some form of special health care need ([Health Resources & Services Administration, 2016](#)), and most CSHCN will reach adulthood. Despite increases in survival, these

youth are less likely to finish high school, pursue secondary educational opportunities, maintain a fulltime job, or live independently. There has been a recent focus on transition as a way to prepare these youth for adulthood with the ultimate goal of improving health, vocational, and social outcomes. However, what is considered a successful transition to adulthood has yet to be defined, because there has been inconsistency in transition preparation and what outcomes define a successful transition (Coyne, Hallowell, & Thompson, 2017). There are differences between *transfer*, which is the act of changing from one provider to another, and *transition*, which is the process of preparation for patients, family members, and providers for the actual transfer of care. For the purpose of this review, *transition* refers to the process or program to prepare for the transfer of care, whereas *transfer* relates to the actual event of transferring care from one provider to another.

Given the difficulty in studying transition planning and success, use of secondary data for transition research is imperative because it allows for control of confounding factors and for the analysis of trends over time (Clarke & Cossette, 2000). The Maternal and Child Health Bureau (MCHB), a division of the HRSA, has focused on improving systems of care and support for CSHCN and their families. One of the MCHB core goals is for all CSHCN to receive the necessary services to make transitions in all aspects of life. To meet the MCHB core outcome on transition, the following criteria must be met: (a) the youth's provider discussed (or the parent indicated that such discussions were not needed) transitioning to doctors who treat adults, (b) the youth's provider discussed (or the parent indicated that such discussions were not needed) changing health needs as youth becomes an adult, (c) the youth's provider discussed (or the parent indicated that such discussions were not needed) how to maintain health insurance as an adult, and (d) the provider usually or always encourages the youth to take age-appropriate responsibility for managing his or her own health records (Data Resource for Child and Adolescent Health, 2011).

To monitor success in achieving the MCHB core outcomes, HRSA funding supported the development of the National Survey of Children with Special Health Care Needs (NS-CSHCN; n.d.), a national survey that provides data on the health status and

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health services needs of children. The NS-CSHCN is a cross-sectional telephone survey conducted using a random sample of U.S. households via a two-part survey that collects information on 20 health conditions from allergies to congenital heart disease. The first part of the survey identifies households with CSHCN. The second part is a more in-depth survey on the health and well-being of one of the children in the household. This survey has been conducted three times, initially in 2001 and most recently in 2009-2010. The design and methodology used for the NS-CSHCN have been described previously (Data Resource for Child and Adolescent Health, 2016). Over the three data collection periods, the interpretation of the MCHB core outcome on transition has not changed. The NS-CSHCN have been used in a variety of ways, but it is unclear how it has been used to study transition related outcomes. The purpose of this systematic review was to describe methodologic considerations using the NS-CSHCN for transition research in terms of variable inclusion and definition of transition outcomes while providing suggestions for using the NS-CSHCN for future transition-related research.

## METHODS

This systematic review was conducted using the available biomedical literature in accordance with the guidelines outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement (i.e., PRISMA; Moher et al., 2015).

### Data Search and Eligibility Criteria

PubMed, OVID, MEDLINE, and CINAHL were searched in December 2016 for peer-reviewed original research included in the databases. The search strategy used a combination of Medical Subject Heading (i.e., MeSH) terms and key word searches that included the terms *NS-CSHCN* and *National Survey of Children with Special Health Care Needs*. The search was limited to English-only articles; otherwise there were no limits applied. After searching by key words, all titles and abstracts were reviewed by hand, and inclusion criteria were applied manually. The study selection and inclusion criteria are detailed in the Figure. Abstracts were reviewed if they included the use of the NS-CSHCN for any analysis. All studies were independently assessed for eligibility by two reviewers (B.C. and S.H.). Inclusion criteria included (a) use of the NS-CSHCN and (b) any component of transition included as an outcome variable. Non-English articles and those that did not use data from the NS-CSHCN in analysis were excluded.

Full-text articles were assessed for eligibility, with only two articles excluded at this stage because they used the NS-CSHCN to design their study but did not use actual data from the NS-CSHCN dataset in empirical

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