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# Protocol\_Psychosocial Support and Care for Children with Special Health Care Needs and Their Families: A Scoping Review for Enhancing the Care System

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## ABSTRACT

**Introduction:** The increasing number of children with special health care needs (CSHCN) due to advancements in medical technology indicates the need to strengthen care systems. This review summarizes findings on care and support for CSHCN and their families.

**Method:** In this scoping review, an extensive search strategy included articles searched in December 2023 using databases such as PubMed, Web of Science, CINAHL, ERIC, The Cochrane Library, and Ichushi (Japanese language).

**Results:** Following a comprehensive search and screening process, 58 articles were selected and categorized into five themes based on type of care and support: care systems centered on hospitals and other specialized institutions, care coordination, human resources, and programs aimed at achieving complex care.

**Discussion:** This study underscores the importance of establishing effective care systems, with a function responsible for continuous and smooth care coordination from multiple perspectives, for the well-being of CSHCN and their families.

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We are still developing and  
optimizing this protocol

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## Review Protocol

### 1 Review Protocol

((cshcn[tiab]) OR ("children with special needs"[tiab] OR "children with special health care needs"[tiab] OR "children with special healthcare needs"[tiab]) OR ("children with special needs"[tiab] OR "children with special health care needs"[tiab]) AND (care[tiab] OR cares[tiab] OR "support\*" [tiab] OR "service\*" [tiab]))

Publication date ↓

The definition of CSHCN was clarified by the journal in 1998 or later.

Target language: English (including Japanese for medical journals)

Aim: To organize and integrate previous findings on care and support for CSHCN and their families.

Screening will be conducted by two independent researchers, and any disagreements will be discussed and agreed upon.

Agreement will be reached on any disagreements. The number of applicable cases using the above search formula is expected to be approximately 1,500. To increase consistency among researchers, 10% of the cases will be screened at the beginning of the screening.

To improve consistency among researchers, a calibration exercise of screening will be conducted by extracting about 10% of the references at the beginning of the screening.

(a preliminary screening exercise in which a pilot screening is conducted to check the criteria and the degree of agreement and to discuss the results if necessary).

#### Title screening

Title screening will be used to

The screening of literature will be

conducted to determine if it is relevant to children with special health care needs (similar concepts such as medically complex children should be included).

(Similar concepts such as "medically complex children" should be included.)

Is the content related to the challenges, difficulties, care and support for the child and family?

Is the content related to support for living, growth, development, and parenting, rather than treatment of disease?

The following are excluded.

xx Contents related to oral care and dental treatment, CSHCN screener, and medical decision making, disaster preparedness, ADL measurement for children, Medicaid and Medicaid policy, stress biomarker development, adult transition support,

#### Abstract/Full-text screening

Does the abstract include a description of challenges, difficulties, or care for children and families?

(Some abstracts include care and support in the title but are limited to a survey of the current situation.)

(Some of the abstracts included care and support in the title but were limited to a survey of the current situation.

×(Some of the reports included care and support in the title, but were limited to a survey of the current situation, Adverse Childhood Experiences (ACE) survey only, study skills, barriers to respite but not respite care, focal points.

not respite care, existing scoping reviews

with a different focus, adult transitional support evaluations only,

Hospitalization Best Practices Alerts,

insurance programs in US states