systems & policy RESEARCH NETWORK for Children and Youth with Special Health Care Needs and Their Families

FAMILY VOICES®

Measuring Quality of Life in CYSHCN

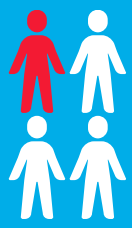
Quality of Life (QoL) Measures Developed or Validated in Children or Youth with Special Healthcare Needs (CYSHCN)

BACKGROUND

The current way we measure QoL in CYSHCN is not reflective of their true quality of life.

WHO ARE CYSHCN?

CYSHCN are **those who have, or are at risk for, chronic conditions** and require health care use beyond that required generally; they make up at least one in four of the U.S. child population.



WHY IS THIS WORK IMPORTANT?

There is a **shift from CYSHCN merely surviving** to ensuring that this population has **access to care and environments that support a dignified life.** QoL refers to the ability of a person to enjoy the values and possibilities of their life.

CURRENT ISSUES

Existing QoL measures are often insufficient for capturing the many aspects of the lives of CYSHCN and their families.

There are concerns about **bias when focusing on physical function** as it may not reflect the true quality of life for children with disabilities.

PURPOSE

We conducted a scoping review, a process that gathers and organizes the available evidence on a topic, **to describe the development and validation of measurement tools for assessing QoL in CYSHCN**. A scoping review can help identify gaps in the topic being studied.

METHODS



Literature Search

We conducted a literature search for publications on concepts of QoL, complex medical conditions, children, scales and measurements including grey literature such as reports from major national organizations and foundations.

Literature Review

The study team reviewed titles and abstracts to determine if they met the criteria, including QoL measures for children ages 0-18 with special needs, chronic conditions, or disabilities. **Excluded studies focused only on physical function, adults, or caregiver/family QoL.**

Data Extraction

The included articles were categorized into groups with **analysis focused on** studies exploring the **development and validation of QoL measures** and translation and adaptation studies of **QoL measures in different languages and for different populations.**



RESULTS



We found **over 11,000 articles on QoL measures for CYSHCN.**

After the review process, we identified **305 studies that covered 41 different QoL measures.**



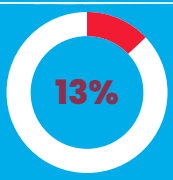


184 studies validated existing measures in new CYSHCN populations or settings.

63 studies validated measures in a new language, 40 languages across 53 countries.

CHALLENGES

Only 13% of studies involved CYSHCN in initial measure development.





Over 40 QoL measures available, but **inconsistency** in their development and validation **make comparison and clinical application challenging.**

Measures that focus on physical ability may misrepresent QoL for many children with disabilities.



WHAT'S NEXT?

More Qualitative Research

Call for **more research that explores the "how" and "why" measures should be adapted**, and their use and development of new measures to assess QoL in CYSHCN





Involve Families

Incorporate the perspectives of CYSHCN and their families in the development of QoL measurement.

Explore Best Practices

Future research on **best practices for QoL measurement** in CYSHCN.





Reevaluate Existing Measures

Future research on **whether existing QoL measures assess the broad dimensions of QoL** relevant to CYSHCN

CYSHCNet conducts research to help children and youth with special health care needs (CYSHCN), their families, and health systems thrive. This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under UA6MC31101 Children with Special Health Care Needs Research Network. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

systems & policy
RESEARCH NETWORK
for Children and Youth with Special Health Care Needs and Their Families

FAMILY VOICES®