RECOMMENDATIONS FOR QUALITY OF LIFE OUTCOMES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

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PREPARED BY: THE TITLE V CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS TECHNICAL ADVISORY PANEL

CHILDREN'S MEDICAL SERVICES

Introduction

Payment for clinical practice is undergoing a transformation in the United States. Traditional fee-for-service is being replaced by a variety of mechanisms such as pay-for-performance, bundled care for discrete health conditions, and accountable care organizations. The goal of such arrangements is to provide financial incentives to reward higher quality and to reduce costs. Value-based payment (VBP) has the potential to improve health outcomes at an individual and population level. Because health is influenced by where people live, learn, work and play, VBP allows clinicians and organizations to address the roots of child health.

How best to measure quality is one critical component of VBP. Attempts to lower costs without close monitoring of quality can lead to reduced access to necessary medical care. Inappropriate quality measures can incentivize less effective clinical practice. Perhaps most importantly, quality measures that are relatively easy to gather at a population level tend to reflect process rather than outcomes. Billing records can indicate whether there was a well child visit or a vaccine given; in general they do not provide data on whether a procedure was medically necessary (e.g. antibiotic prescription) or whether the outcome was a good one.

Children and youth with special health care needs (CYSHCN) are at particular risk in the move to VBP. By definition CYSHCN require greater levels of health care services, which leads to higher costs. Furthermore, CYSHCN represent a diverse range of thousands of rare health conditions which are not easily monitored at a population level. Although there is value to a VBP system that increases childhood vaccine rates, an approach that measures only general processes is insufficient for a child with cancer or a complex metabolic disorder. The Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0 provides a national framework for ensuring that the needs of CYSHCN and their families are met in new payment arrangements. A copy of the report is available at http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20for%20Systems%20of%20Care%20for%20Children%20and%20Youth%20with%20Special%20Health%20Care%20Needs%20Version%202.0.pdf

Recognizing the need to enhance measures currently utilized by entities serving CYSHCN, the State Surgeon General of the Florida Department of Health created the Title V Children and Youth with Special Health Care Needs Technical Advisory Panel (CYSHCN TAP) and charged the Panel with providing recommendations on health outcome measures for CYSHCN, including quality of life measures. The CYSHCN TAP includes representatives from professional pediatric organizations, pediatric practitioners and youth and families. A copy of the CYSHCN TAP charter and a list of Panel members can be found at http://www.floridahealth.gov/programs-and-services/childrens-health/cms-specialty-programs/title-v-tap/index.html.

The CYSHCN TAP reviewed current measures used to evaluate child health outcomes in the CMS Plan, a specialty plan option under Florida's Statewide Medicaid Managed Care (SMMC) Managed Medical Assistance (MMA) Program. The CYSHCN also reviewed additional tools and surveys to examine their potential for indicating improved health outcomes for CYSHCN. Additionally, the CYSHCN TAP released a draft consensus statement to seek input from the public and other stakeholders and can be found at the link noted above. This report highlights tools and surveys available to entities that serve CYSHCN and provides recommendations for organizations to consider incorporating into their initiatives to improve health outcomes for CYSHCN.

Review of Current and Potential Quality Measures

In a series of public meetings, the CYSHCN TAP reviewed and considered current and potential tools measuring a variety of outcomes, while considering their usefulness in evaluating quality health outcomes for CYSHCN, including children with medical complexity (CMC). The following Appendices provide detail into the materials reviewed.

- Appendix A: Florida CMS Current and Potential Performance Measures and Quality of Life Surveys
- Appendix B: State of Florida Technical Advisory Group Research: Quality of Life Measures
- Appendix C: CYSHCN TAP Articles and Additional Information

Recommendations

The CYSCHN TAP unanimously agreed that there is great value in measuring both the child's and the family's overall health and well-being. If quality of life is routinely measured, then child health programs can focus on improving the outcomes that matter most to children and families, including the degree to which a child is able to meet his or her potential. Programs will also have further incentive to aim at the roots of health, and to consider activities that address health conditions in homes, neighborhoods, and schools. Improved child and family well-being can increase work productivity and school attendance.

The CYSHCN TAP recognizes that although there is no single quality of life tool or survey currently available to adequately measure quality of life outcomes in all situations, there are many measures available for specific purposes. The National Academy for State Health Policy released a compendium of measures that align with The Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0. The measures compendium can be found at https://nashp.org/national-standards-compendium/. Measuring quality of life typically requires surveying CYSHCN and/or their families, which can be an expensive and time-consuming process. As such, the CYSNCH TAP agreed that attempts to measure quality of life should consider the burden on youth and families, as well as on the limited resources of health care organizations.

In conclusion the CYSHCN TAP recommends that child health programs include at least one measure of child/youth quality of life and at least one measure of family well-being. Specific measures will vary depending on the CYSHCN population being served and a program's specific goals. Standardized measures should be chosen to allow state and national comparisons and should be used regularly to track progress and guide quality improvement activities.

FLORIDA CMS CURRENT AND POTENTIAL PERFORMANCE MEASURES AND QUALITY OF LIFE SURVEYS

MEASURING SATISFACTION, QUALITY OF CARE AND QUALITY OF LIFE: CURRENT CMS DATA COLLECTION

CMS currently utilizes a combination of process and outcomes measures that measure satisfaction, quality of care and quality of life through multiple data collection methods. **Outcome measures** consist of clinical topic areas that are targeted for improvement. These include mortality rates, readmission rates, surgical site infection rates, satisfaction and access to care. **Process measures** quantify the specific steps in a process that lead to outcome metrics. These include the time that it takes for an individual to be seen by a physician, the number of prescriptions that an individual has, or the percentage of individuals with a particular diagnosis receiving preventive tests.

CMS participates in the **Consumer Assessment of Healthcare Providers and Systems (CAHPS)** survey. Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys ask consumers and patients to report on and evaluate their experiences with health care. These surveys cover topics that are important to consumers and focus on aspects of quality that consumers are best qualified to assess, such as the communication skills of providers and ease of access to health care services. [1]

CMS utilizes the **Healthcare Effectiveness Data and Information Set (HEDIS)** to measure quality of care. HEDIS is a tool used by more than 90 percent of America's health plans to measure performance on important dimensions of care and service. Altogether, HEDIS consists of 94 measures across 7 domains of care. Because so many plans collect HEDIS data, and because the measures are so specifically defined, HEDIS makes it possible to compare the performance of health plans on an "apples-to-apples" basis.[2]

CMS also utilizes specific health outcomes **measures related to the targeted child health population**. These measures come from a variety of sources such as the Title V National Performance Measures, the Centers for Medicare and Medicaid Services (CMS) Core Child and Adult performance measures set, the National Survey of Children's Health, the Association of Maternal and Child Health Programs, and process measures related to the operation of CMS.

In the future, CMS will implement a **health-related quality of life survey** consisting of self-reported and parent-reported measures of physical, emotional/mental and social health for children.

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[1] More information on CAHPs can be found at: https://www.ahrq.gov/cahps/about-cahps/index.html

[2] More information on HEDIS can be found at: http://www.ncqa.org/tabid/59/Default.aspx

CURRENT MEASURES AND POTENTIAL NEW DATA COLLECTION METHODS

CURRENT CMS PERFORMANCE MEASURES

HEALTHCARE EFFECTIVENESS DATA AND INFORMATION SET (HEDIS)

- Adolescent Well-Care Visits - (AWC)
- Antidepressant Medication Management - (AMM)
- Adult BMI Assessment
- Childhood Immunization Status – (CIS) – Combo 2 and 3
- Comprehensive Diabetes Care – (CDC)
  - Hemoglobin A1c (HbA1c) testing
  - HbA1c poor control
  - HbA1c control (<8%)
  - Eye exam (retinal) performed
  - Medical attention for nephropathy
- Follow-up Care for Children Prescribed ADHD Medication – (ADD)
- Immunizations for Adolescents – (IMA)
- Chlamydia Screening in Women – (CHL)
- Prenatal and Postpartum Care – (PPC)
- Medication Management for People with Asthma – (MMA)
- Well-Child Visits in the First 15 Months of Life – (W15)
- Well-Child Visits in the Third, Fourth, Fifth and Sixth Years of Life – (W34)
- Children and Adolescents’ Access to Primary Care Practitioners - (CAP)
- Initiation and Engagement of Alcohol and Other Drug Dependence Treatment - (IET)
- Ambulatory Care - (AMB)
- Lead Screening in Children – (LSC)
- Annual Monitoring for Patients on Persistent Medications - (MPM)
- Frequency of Ongoing Prenatal Care - (FPC)
- Metabolic Monitoring for Children and Adolescents on Antipsychotics – (APM)
- Use of Multiple Concurrent Antipsychotics in Children and Adolescents - (APC)
- Follow-Up After Emergency Department Visit for Mental Illness– (FUM)
- Follow-Up After Emergency Department Visit for Alcohol and Other Drug Dependence Treatment – (FUA)
- Diabetes Screening for People with Schizophrenia or Bipolar Who are Using Antipsychotic Medications SSD
- ED visits per 1,000 member months

HEDIS & CMS PLAN-DEFINED

- Follow-Up after Hospitalization for Mental Illness – (FHM)

CMS PLAN-DEFINED

- Mental Health Readmission Rate – (RER)
- Transportation Timeliness (TRT)
- Transportation Availability (TRA)
- Highly Active Anti-Retroviral Treatment (HAART)
- HIV-Related Outpatient Medical Visits (HIVV)

CHILD CORE SET

- Weight Assessment and Counseling for Nutrition and Physical Activity for Children/Adolescents: Body Mass Index Assessment for Children/Adolescents – (WCC)

ADULT CORE SET

- HIV Viral Load Suppression - (VLS)

TITLE V NATIONAL PERFORMANCE MEASURE (HRSA AND AHRQ DEVELOPED MEASURES)

- Percent of children, ages 10 through 71 months, receiving a developmental screening using a parent-completed screening tool
- Rate of hospitalization for non-fatal injury per 100,000 children ages 0 through 9 and adolescents 10 through 19
- Inpatient Utilization Discharges/1,000 Member Months/Years.
- Percent of adolescents with a preventive medical visit in the past year

CENTERS FOR MEDICARE AND MEDICAID SERVICES AGES 12-21 (NQF #3148)

- Adolescent Depression: Screening for Depression

PROCESS MEASURES

- New enrollees are provided a documented initial health assessment within 30 days of enrollment in the CMS Plan and a completed person centered plan within 45 days of enrollment.
- Use of Patient Centered Medical Homes (PCMHs)
- Call Answer Timeliness (CAT)
- Well-child visit rate of at least 80%
- 80% well-child visit participation rate

NATIONAL SURVEY OF CHILDREN'S HEALTH (NSCH)

- Proportion of families who report their child received services in a medical home
    - Numerator: Children ages 0–17 whose health care meets Medical Home criteria
    - Denominator: Children ages 0–17 years

ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

- Percentage of youth reporting transition in place

QUALITY OF LIFE SURVEYS

"When evaluating medical interventions within the medical health services system, not only the quality of life of adults but also that of children and adolescents can be viewed as an important outcome criterion. The use of medical assistance affects not only somatic, but also emotional and social parameters; it is therefore necessary to shed light on the state of children and adolescents from their own point of view. Research into the quality of life of children and adolescents is particularly important also because the number of children and adolescents with chronic disorders, including psychiatric disorders, has increased despite the impressive progress made in medicine."[3]

CMS will implement a quality of life survey such as the PedsQL for Ages 2-18 or a similar NIH recommended tool such as the following.

Below are two options for quality of life surveys. These surveys were recommended for consideration because they both demonstrate high reliability. The PedsQL covers a broad spectrum of ages and can be completed in a short time in most settings. The NIH tools are free, need no preparation, are "respondent ready," and have rigorous scientific development.

QUALITY OF LIFE SURVEYS	FEATURES	CONSIDERATIONS
PedsQL[4] (Ages 2–18)	• 23 questions on physical, emotional, social, school functioning • Four minutes • Condition specific available with additional modules in the development and planning stages	• Wide age range • Condition specific modules available • Short screen • The Pediatric Quality of Life Inventory has already been used in numerous different research settings, and is characterized by a high reliability.[5]

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[3] https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/EvidenceBasedStrategyMeasures/7 and

[4] http://www.pedsql.org/about_pedsql.html

[5] https://mchb.tvisdata.hrsa.gov/PrioritiesAndMeasures/EvidenceBasedStrategyMeasures/7

NIH Tools[6]	• 21 questions including global health, mental health, physical health, and social health	• The PROMIS pediatric quality of life measures are specifically for persons with health conditions as well as the general population. It includes self-report measures (ages 8-17) and proxy measures (ages 5-17) for pediatric populations. It can be administered through paper and pencil or computer administration. • Multiple options for length of survey and short forms

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[6] http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures

NATIONAL SURVEY OF HEALTH

The National Survey of Children with Special Health Care Needs (NS-CSHCN) was conducted three times between 2001 and 2010.[7] The NS-CSHCN was a telephone survey led by the National Center for Health Statistics at the Centers for Disease Control and Prevention under the direction and sponsorship of the federal Maternal and Child Health Bureau. The survey is currently being integrated into the National Survey of Children's Health[8].

1. Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.
   - Denominator: CSHCN age 0–17 years
   - Numerator: CSHCN whose families usually or always feel that they are partners in decision making around issues important to their child's health; Outcome not successfully achieved
2. Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home
   - Survey Items: A total of 19 different survey questions are used to develop the overall composite I score for having a Medical Home
   - Denominator: CSHCN age 0–17 years
   - Numerator: CSHCN receiving adequate care on all needed components of medical home assessed by the survey; CSHCN who did not achieve this outcome
3. Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need
   - Denominator: CSHCN age 0–17 years
   - Numerator: CSHCN whose private and/or public insurance coverage is continuous and adequate to meet the child's health needs; CSHCN who did not achieve this outcome
4. Outcome #4: CSHCN who are screened early and continuously for special health care needs
   - **Denominator:** CSHCN age 0–17 years

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[7] http://www.childhealthdata.org/home

[8] https://mchb.hrsa.gov/data/national-surveys

- **Numerator:** CSHCN who had at least 1 preventive medical visit and at least 1 preventive dental visit in the past 12 months; CSHCN who did not achieve this outcome

5. Outcome #5: CSHCN who can easily access community based services
   - Denominator: CSHCN age 0–17 years
   - Numerator: CSHCN whose families report no difficulties or frustration accessing services needed for their child in the past 12 months; CSHCN who did not achieve this outcome
6. Youth with special health care needs receive the services necessary to make appropriate transitions to adult health care, work, and independence.
   - National Performance Measure #12: Percent of adolescents with special health care needs who received services necessary to make transitions to adult health care
   - **Denominator:** CSHCN age 12–17 years
   - **Numerator:** Number of adolescents with special health care needs, age 12–17 years, whose families report that they received the services necessary to transition to adult health care
7. In addition, in 2016, the National Survey for Children's Health collected data. See the performance measure maps in Attachment 1.

STANDARDS FOR SYSTEMS OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS VERSION 2.0

In June, 2017, the Association of Maternal and Child Health Programs updated their guidance regarding characteristics of a comprehensive, quality system of care for CYSHCN. The guidance's reference to performance measures included the 2013 Special Needs Structure and Process measures from NCQA, specifically referencing element 2 Improving Member Satisfaction.[9] These performance measures include three elements including:

- Element A: Assessment of Member Satisfaction

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[9] https://www.cms.gov/Medicare/Health-Plans/Medicare-Advantage-Quality-Improvement-Program/Downloads/SandP_2012_SNP_Performance-Report_09_20_2013.pdf accessed on 9/15/2017.

- Element B: Opportunities for Improvement
- Element C: Improving Satisfaction

In addition, other SNP performance measures have aspects that may assist CMS in improving care management, transition to care and other aspects of care:

- SNP 1 on Complex Case Management
- Element A: Identifying Members for Case Management
- Element B: Access to Case Management
- Element C: Case Management Systems
- Element D: Frequency of Member Identification
- Element E: Providing Members with Information
- Element F: Case Management Process
- Element G: Individualized Care Plan
- Element H: Informing and Educating Practitioners
- Element I: Satisfaction with Case Management
- Element J: Analyzing Effectiveness/Identifying Opportunities
- Element K: Implementing Interventions and Follow-up
- Evaluation SNP 3: Clinical Quality Improvements Element A: Clinical Improvements
- SNP 4: Care Transitions
- Element A: Managing Transitions
- Element B: Supporting Members Through Transitions
- Element C: Analyzing Performance
- Element D: Identifying Unplanned Transitions
- Element E: Analyzing Transitions

- Element F: Reducing Transitions
- SNP 5: Institutional SNP Relationship with Facility
- Element A: Monitoring Members’ Health Status
- Element B: Monitoring Changes in Members’ Health Status
- Element C: Maintaining Members’ Health Status
- SNP 6: Coordination of Medicare and Medicaid Coverage
- Element A: Coordination of Benefits for Dual-Eligible Members
- Element B: Administrative Coordination of D-SNPs
- Element C: Administrative Coordination for Chronic Condition and Institutional Benefit Packages
- Element D: Service Coordination
- Element E: Network Adequacy Assessment

ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS: LIFE COURSE INDICATORS

AMCHP launched a project designed to identify and promote a standardized set of indicators that can be applied to measure progress using the life course approach to improve maternal and child health.[10] A National Expert Panel guided the framework for the project, and the selection of the final set of indicators took place over a 12-month collaborative process with seven state teams: Florida, Iowa, Louisiana, Massachusetts, Michigan, Nebraska and North Carolina. The teams distilled 413 proposed indicators down to approximately 100 by assessing the indicators on three data and five life course criteria. The final set of 59 were selected by a voting procedure at an in-person meeting in June 2013, where states discussed supporting written narratives for each indicator after consulting state expertise and the literature. On December 12, 2013, AMCHP staff made a series of technical corrections and updates to components of the final life course indicators, including numerators and denominators, to further clarify their calculation and use. Below is a subset of these indicators for consideration.

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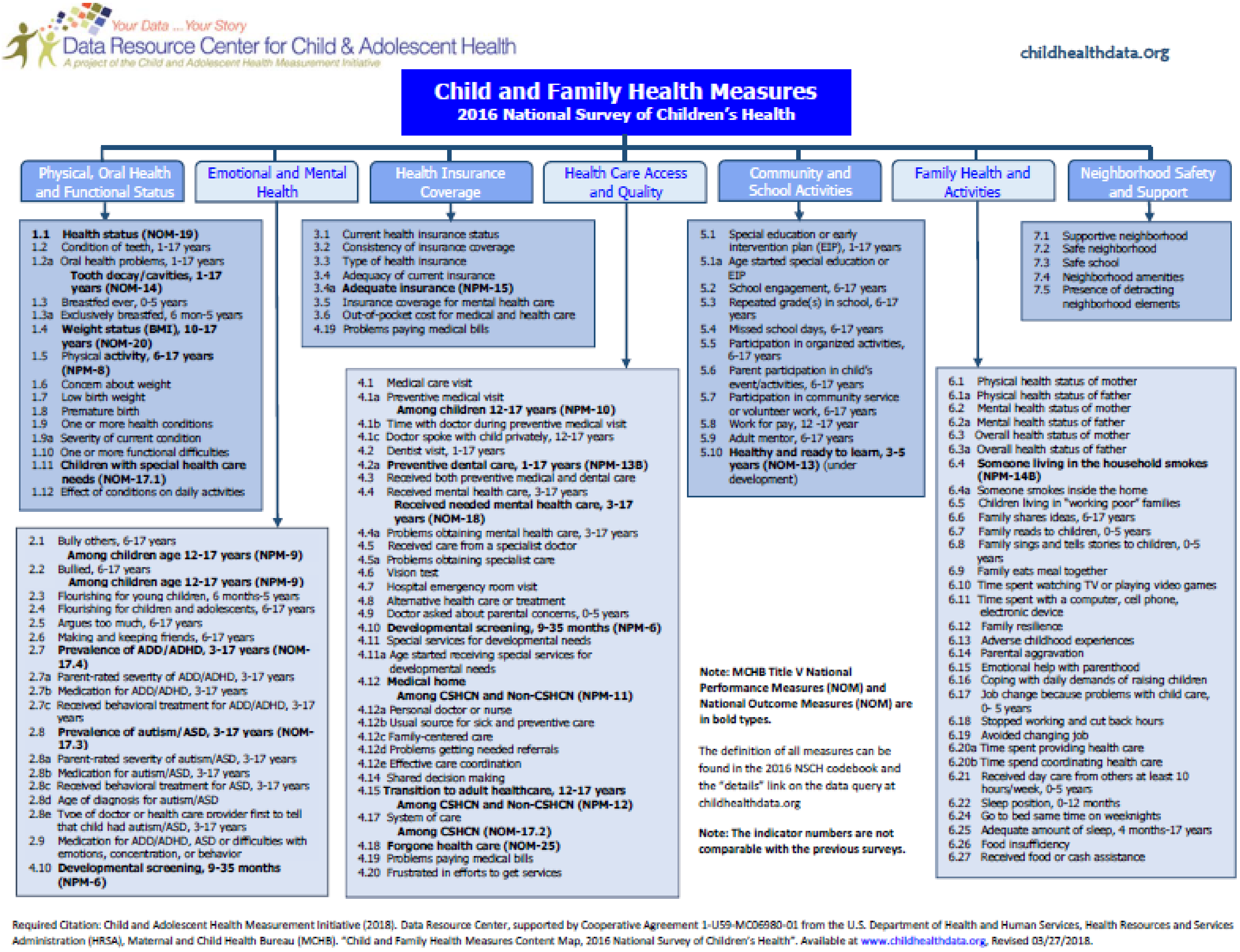
[10] http://www.amchp.org/programsandtopics/CYSHCN/Pages/default.aspx accessed on 9/18/2017

IDENTIFIER	THEMATIC CATEGORY	INDICATOR NAME	BRIEF DESCRIPTION
LC-1	Childhood Experiences	Adverse Childhood Experiences Among Adults	Prevalence of adverse childhood experiences
LC-2	Childhood Experiences	Prevalence of Adverse Childhood Experiences Among Children	Prevalence of adverse childhood experiences among children
LC-3	Childhood Experiences	Substantiated Child Maltreatment	Substantiated child maltreatment including experience of physical abuse, neglect or deprivation of necessities, medical neglect, sexual abuse, psychological or emotional maltreatment
LC-4	Community Health Policy	Breastfeeding Support – Baby Friendly Hospitals	Proportion of births occurring in baby friendly hospitals
LC-5	Community Health Policy	Fluoridation	Proportion of population served by community water systems that received optimally fluoridated water
LC-14	Discrimination and Segregation	Perceived Experiences of Discrimination Among Children	Percentage of children who experienced discrimination in the past year (parent report)
LC-57	Social Capital	4th Grade Proficiency	Percentage of fourth graders scoring proficient or above on math and reading



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Child and Family Health Measures
2016 National Survey of Children's Health

Physical, Oral Health and Functional Status

1.1 Health status (NOM-19)
1.2 Condition of teeth, 1-17 years
1.2a Oral health problems, 1-17 years
Tooth decay/cavities, 1-17 years (NOM-14)
1.3 Breastfed ever, 0-5 years
1.3a Exclusively breastfed, 6 mon-5 years
1.4 **Weight status (BMI), 10-17 years (NOM-20)**
1.5 Physical **activity, 6-17 years (NPM-8)**
1.6 Concern about weight
1.7 Low birth weight
1.8 Premature birth
1.9 One or more health conditions
1.9a Severity of current condition
1.10 One or more functional difficulties
1.11 **Children with special health care needs (NOM-17.1)**
1.12 Effect of conditions on daily activities

Emotional and Mental Health

2.1 Bully others, 6-17 years
Among children age 12-17 years (NPM-9)
2.2 Bullied, 6-17 years
Among children age 12-17 years (NPM-9)
2.3 Flourishing for young children, 6 months-5 years
2.4 Flourishing for children and adolescents, 6-17 years
2.5 Argues too much, 6-17 years
2.6 Making and keeping friends, 6-17 years
2.7 **Prevalence of ADD/ADHD, 3-17 years (NOM-17.4)**
2.7a Parent-rated severity of ADD/ADHD, 3-17 years
2.7b Medication for ADD/ADHD, 3-17 years
2.7c Received behavioral treatment for ADD/ADHD, 3-17 years
2.8 **Prevalence of autism/ ASD, 3-17 years (NOM-17.3)**
2.8a Parent-rated severity of autism/ASD, 3-17 years
2.8b Medication for autism/ASD, 3-17 years
2.8c Received behavioral treatment for ASD, 3-17 years
2.8d Age of diagnosis for autism/ASD
2.8e Type of doctor or health care provider first to tell that child had autism/ASD, 3-17 years
2.9 Medication for ADD/ADHD, ASD or difficulties with emotions, concentration, or behavior
4.10 **Developmental screening, 9-35 months (NPM-6)**

Health Insurance Coverage

3.1 Current health insurance status
3.2 Consistency of insurance coverage
3.3 Type of health insurance
3.4 Adequacy of current insurance
3.4a **Adequate insurance (NPM-15)**
3.5 Insurance coverage for mental health care
3.6 Out-of-pocket cost for medical and health care
4.19 Problems paying medical bills

Health Care Access and Quality

4.1 Medical care visit
4.1a Preventive medical visit
Among children 12-17 years (NPM-10)
4.1b Time with doctor during preventive medical visit
4.1c Doctor spoke with child privately, 12-17 years
4.2 Dentist visit, 1-17 years
4.2a **Preventive dental care, 1-17 years (NPM-13B)**
4.3 Received both preventive medical and dental care
4.4 Received mental health care, 3-17 years
Received needed mental health care, 3-17 years (NOM-18)
4.4a Problems obtaining mental health care, 3-17 years
4.5 Received care from a specialist doctor
4.5a Problems obtaining specialist care
4.6 Vision test
4.7 Hospital emergency room visit
4.8 Alternative health care or treatment
4.9 Doctor asked about parental concerns, 0-5 years
4.10 **Developmental screening, 9-35 months (NPM-6)**
4.11 Special services for developmental needs
4.11a Age started receiving special services for developmental needs
4.12 **Medical home**
Among CSHCN and Non-CSHCN (NPM-11)
4.12a Personal doctor or nurse
4.12b Usual source for sick and preventive care
4.12c Family-centered care
4.12d Problems getting needed referrals
4.12e Effective care coordination
4.14 Shared decision making
4.15 **Transition to adult healthcare, 12-17 years**
Among CSHCN and Non-CSHCN (NPM-12)
4.17 System of care
Among CSHCN (NOM-17.2)
4.18 **Forgone health care (NOM-25)**
4.19 Problems paying medical bills
4.20 Frustrated in efforts to get services

Community and School Activities

5.1 Special education or early intervention plan (EIP), 1-17 years
5.1a Age started special education or EIP
5.2 School engagement, 6-17 years
5.3 Repeated grade(s) in school, 6-17 years
5.4 Missed school days, 6-17 years
5.5 Participation in organized activities, 6-17 years
5.6 Parent participation in child's event/activities, 6-17 years
5.7 Participation in community service or volunteer work, 6-17 years
5.8 Work for pay, 12 -17 year
5.9 Adult mentor, 6-17 years
5.10 **Healthy and ready to learn, 3-5 years (NOM-13)** (under development)

Family Health and Activities

6.1 Physical health status of mother
6.1a Physical health status of father
6.2 Mental health status of mother
6.2a Mental health status of father
6.3 Overall health status of mother
6.3a Overall health status of father
6.4 **Someone living in the household smokes (NPM-14B)**
6.4a Someone smokes inside the home
6.5 Children living in "working poor" families
6.6 Family shares ideas, 6-17 years
6.7 Family reads to children, 0-5 years
6.8 Family sings and tells stories to children, 0-5 years
6.9 Family eats meal together
6.10 Time spent watching TV or playing video games
6.11 Time spent with a computer, cell phone, electronic device
6.12 Family resilience
6.13 Adverse childhood experiences
6.14 Parental aggravation
6.15 Emotional help with parenthood
6.16 Coping with daily demands of raising children
6.17 Job change because problems with child care, 0- 5 years
6.18 Stopped working and cut back hours
6.19 Avoided changing job
6.20a Time spent providing health care
6.20b Time spend coordinating health care
6.21 Received day care from others at least 10 hours/week, 0-5 years
6.22 Sleep position, 0-12 months
6.24 Go to bed same time on weeknights
6.25 Adequate amount of sleep, 4 months-17 years
6.26 Food insufficiency
6.27 Received food or cash assistance

Neighborhood Safety and Support

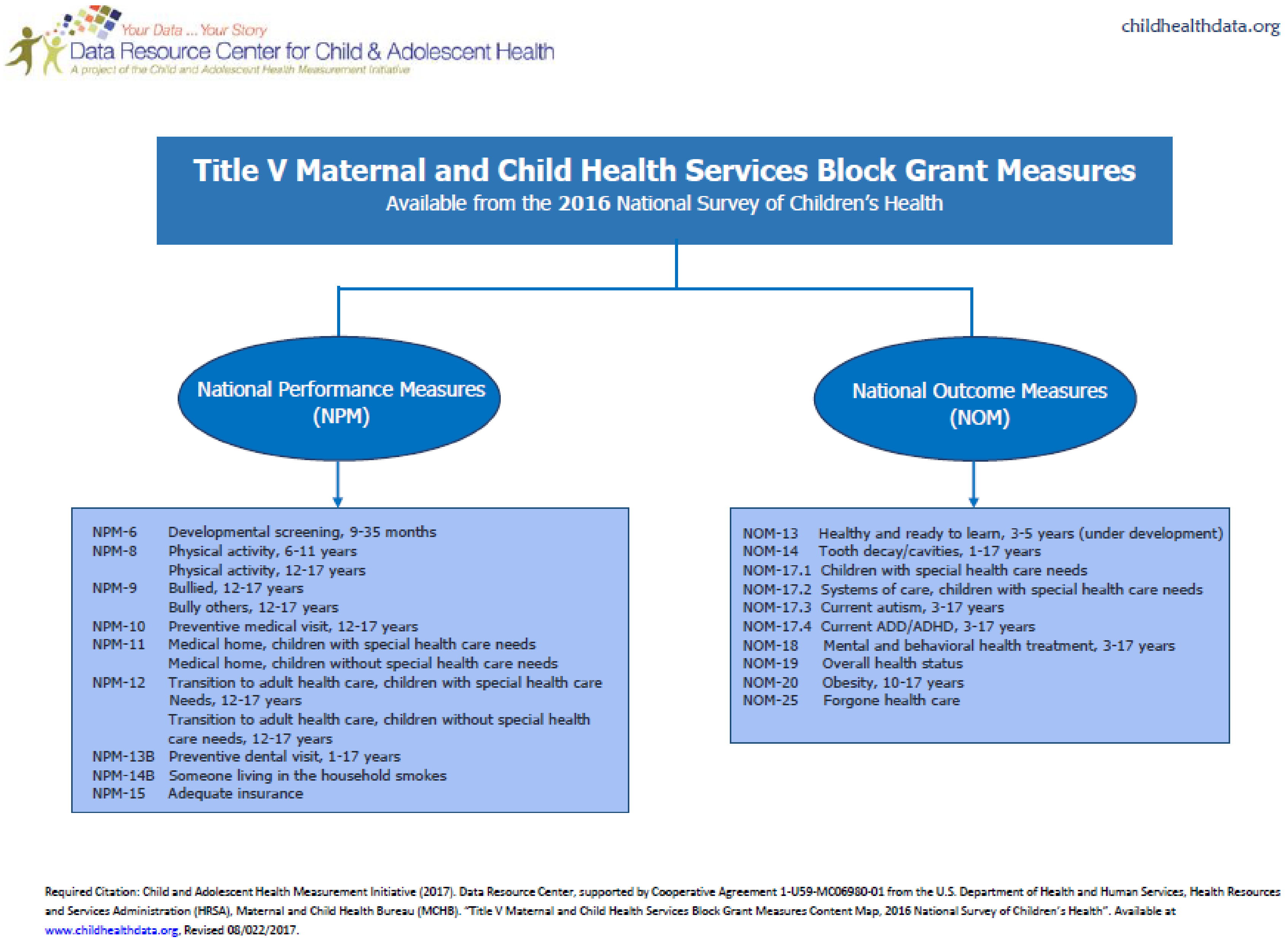
7.1 Supportive neighborhood
7.2 Safe neighborhood
7.3 Safe school
7.4 Neighborhood amenities
7.5 Presence of detracting neighborhood elements

Note: MCHB Title V National Performance Measures (NOM) and National Outcome Measures (NOM) are in bold types.

The definition of all measures can be found in the 2016 NSCH codebook and the "details" link on the data query at childhealthdata.org

Note: The indicator numbers are not comparable with the previous surveys.

Required Citation: Child and Adolescent Health Measurement Initiative (2018). Data Resource Center, supported by Cooperative Agreement 1-U59-MC06980-01 from the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). "Child and Family Health Measures Content Map, 2016 National Survey of Children's Health". Available at www.childhealthdata.org, Revised 03/27/2018.



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Title V Maternal and Child Health Services Block Grant Measures

Available from the **2016** National Survey of Children's Health

National Performance Measures (NPM)

NPM-6	Developmental screening, 9-35 months
NPM-8	Physical activity, 6-11 years Physical activity, 12-17 years
NPM-9	Bullied, 12-17 years Bully others, 12-17 years
NPM-10	Preventive medical visit, 12-17 years
NPM-11	Medical home, children with special health care needs Medical home, children without special health care needs
NPM-12	Transition to adult health care, children with special health care Needs, 12-17 years Transition to adult health care, children without special health care needs, 12-17 years
NPM-13B	Preventive dental visit, 1-17 years
NPM-14B	Someone living in the household smokes
NPM-15	Adequate insurance

National Outcome Measures (NOM)

NOM-13	Healthy and ready to learn, 3-5 years (under development)
NOM-14	Tooth decay/cavities, 1-17 years
NOM-17.1	Children with special health care needs
NOM-17.2	Systems of care, children with special health care needs
NOM-17.3	Current autism, 3-17 years
NOM-17.4	Current ADD/ADHD, 3-17 years
NOM-18	Mental and behavioral health treatment, 3-17 years
NOM-19	Overall health status
NOM-20	Obesity, 10-17 years
NOM-25	Forgone health care

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STATE OF FLORIDA TECHNICAL ADVISORY GROUP RESEARCH: QUALITY OF LIFE MEASURES

BACKGROUND

The Florida Title V Children and Youth with Special Health Care Needs (CYSHCN) Technical Advisory Panel (TAP) was convened to answer the question, *"how to measure quality of life for children with medical complexity?"* by looking at current and possible measures, including process and quality measures to identify measures that indicate quality health outcomes for CYSHCN. As part of this workgroup, Mercer was requested to compile information regarding the predominant quality of life tools in the industry and interview experts regarding those quality of life tools. TAP members were also invited to comment on the data collected.

There were several key themes and conclusions from the experts and TAP members regarding Quality of Life measures and surveys:

- The use of the data can vary widely and affect the data collection, tool selected, population targeted, etc. See Scenarios below:
  - Scenario 1 - Care Manager/Care Coordinator (CM/CC) Use of QoL Tool - In this scenario, the Quality of Life tool is administered in person by the CM/CC in a home or community setting. The goal of this Quality of Life tool in this setting is to identify child-specific issues that can be addressed through care management. Most or all children receiving care management and/or their care givers complete the quality of life questionnaires annually. The CM/CC is encouraged to read the survey aloud or to modify the wording of the tool to ensure that the child and his/her family understand the questions in a culturally relevant manner (e.g., use of pictures or interpreters). The CM/CC may augment the tool with condition specific Disease Management modules. The CM/CC develops a Plan of Care to address the issues and stressors identified by the tool as well as the medical and psychosocial needs of the child and family.
  - Scenario 2 - Department of Health Measurement across Populations over a Span of Time - The Quality of Life tool is administered by a researcher over the phone or by the respondent accessing an on-line instrument. Individuals in the broader population are sampled to achieve statistically significant results. Not all children and/or caregivers are surveyed annually. The goal of this Quality of Life tool is to empirically measure the population health and quality of life over a span of time. In this circumstance, the tool is used consistently to improve the validity and reliability of responses and allow for data comparisons. Results are consolidated and reported at a population level for systemic improvement. Individual child and family needs are not addressed.

  - Scenario 3 -Treatment of Individuals - In this scenario, the Quality of Life tool is administered by a mental health professional in a practice setting. The results are utilized to identify treatment objectives for individuals with mental health diagnoses. Subsequent testing according to instrument protocols identifies the recovery and resiliency that each individual may be developing through skill-building and other therapeutic interventions. Results are kept confidential and utilized solely by the treating practitioner.

  - Scenario 4 – Tracking improvement at health care providers – In this scenario, the child/family completes a self-administered assessment in conjunction with the health care provider visit or patient portal that is integrated into the Electronic Health Records (EHRs). The result is that providers can see changes over time. In addition, insurers can utilize financial incentives to reimburse providers and/or contractors who provide care exceeding the benchmarks set based on baseline data.

- There is not a single tool that can be used for all uses.

- Quality of Life tools for children under the age of 3 are aimed solely at caregiver quality of life. None of the tools look at the quality of the child's life at this age.

- Implementation factors can vary widely depending upon the use of the data

	Scenario 1 (Development of a Child Plan of Care)	**Scenario 2 (Comparison of Quality of Life across Populations over Time)**	**Scenario 3 (Identify Clinical Treatment Needs)**	**Scenario 4 (Tracking improvement for health care providers)**
Administrator of the tool	Care Manager	Researcher	Clinician	Self-administered assessments integrated into Health care provider EHR data
How widespread the tool is administered	Entire population	Population sample	When clinically relevant	Administered to individuals in waiting rooms or through patient portal

How the data are utilized	Identify and address individual child needs	Identify system issues and recommendations	Identify and address clinical needs of an individual	Identify baseline and improvement/ lack of improvement
Tools suggested	PROMIS in conjunction with Condition Specific Disease Management Modules PROMIS with additional modules of Pediatric Stigma or Neuro Qual	PROMIS	Parenting Stress Index (PSI-Stress) and Stress Index for Parents of Adolescents (SIPA-Stress)	Condition specific measures in addition to more general quality of life measures (PROMIS or PEDS QL with and PSI added)

INITIAL FEEDBACK FROM IDENTIFIED EXPERTS[11]

It is difficult to assess whether a particular tool is applicable and useful without a clear understanding of several factors:

- What is the intended use of the tool? For example, one tool may be useful for informing individual care planning, while another tool may be more useful for studying change in a population over time.
- What are the characteristics of the population? For example, certain tools are useful for people with certain conditions but are not useful in a broader population.
- What infrastructure is available for implementing a tool? For example, some tools may yield meaningful information but cannot be feasibly implemented due to time or resource constraints.

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11 Interviews conducted so far include: Dr. Eyal Cohen (University of Toronto) – pediatrician and researcher. Dr. Cohen's research focuses on children with medical complexity and improving outcomes. Dr. Cohen is currently completing a complex care initiative evaluation in Ontario on a model of care for children with special health care needs with medical complexity. Dr. Nora Fayed is an occupational therapist. Dr. Fayed specializes in the measurement and evaluation of quality of life and self-reported health of children with chronic health conditions. Dr. Fayed has worked for the World Health Organization and is currently working with Dr. Cohen on the evaluation of a complex care initiative.

CHILD QUALITY OF LIFE

PEDSQL™ [12]	KINDL®	PROMIS®
DESCRIPTION		
The PedsQL™ Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL™ Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system.	The KINDL® Questionnaire for Children and Adolescents was developed and tested with a view to remedying the discrepancy between the urgency of the subject 'Quality of Life in Children and Adolescents' and the lack of appropriate measures (Ravens-Sieberer, 2000). In developing it, the goal was to design a short, methodologically suitable and flexible set of instruments which could be: • Completed both by children and adolescents, and by their parents; • Available for different age groups and stages of development; • Used for healthy and ill children (generic approach); and • Extended by means of specific modules (e.g. for different classes of diseases).	PROMIS® (Patient-Reported Outcomes Measurement Information System) is a set of person-centered measures that evaluates and monitors physical, mental and social health in adults and children. PROMIS includes over 300 measures of physical, mental and social health for use with the general population and with individuals living with chronic conditions. PROMIS developed pediatric measures for functions, symptoms, behaviors and feelings.
AGES		
Ages 2– adult— Six versions that are age dependent and can be answered by child or parent (except for toddlers which is parent only)	Ages 3–17— Three versions that are age dependent and can be answered by child or parent	Ages 8–17— Self-report; Ages 5–17— Parent Proxy but has adult measures as well
SELF-REPORT AND PARENT PROXY		

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[2] https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory

PEDSQL™ [12]	KINDL®	PROMIS®
Yes	Yes	Yes
COST		
$26,485 annually for royalty fees and distribution fee of $1,080 for one module and $360 per module for additional modules	Free	Free The NIH toolbox is available as an app for the iPad at the iTunes store (by Glinberg & Associates, Inc) https://itunes.apple.com/us/app/nih-toolbox/id1002228307?mt=8 Users must purchase of a 12-month auto-renewing subscription, for $499.99 + tax. This subscription may be used on any iPad on which the NIH Toolbox app is installed, as long as the same Apple ID used for purchase is entered. After the subscription fee has been charged, the subscription cannot be cancelled.
CREDENTIALS OF STAFF ADMINISTERING		
Persons administering must follow the guidelines for the administration of the PedsQL™	Uses SPSS for analysis	Any — Uses standard written questions and computer scoring
LENGTH		
Basic module has 23 items and there are additional modules for different conditions[13]	24 items — additional modules for children with certain illnesses including adiposity, asthma, diabetes, epilepsy, neuro-dermatitis, oncology and spina bifida	4–12 items completed in less than a minute See research on application to Children with Special Health Care Needs (CSHCN)[14]

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[13] RELATED COA INSTRUMENTS—SEE APPENDIX A

[14] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4893933/ Author manuscript; available in PMC 2017 Jul 1. Published in final edited form as: Qual Life Res. 2016 Jul; 25(7): 1815–1823. Published online 2016 Feb 12. doi: 10.1007/s11136-016-1237-2

PEDSQL™[12]	KINDL®	PROMIS®
THEMES/DOMAINS		
Generic Core Scales • Physical Functioning • Emotional Functioning • Social Functioning • School Functioning Condition-Specific Modules[15]	Six subscales: • Physical • Emotional • Self-Esteem • Family • Friends • School Additional Disease subscale has a filter question and items to measure the child's quality of life with respect to his or her illness. Additional modules in: adiposity, asthma, diabetes, epilepsy, neuro-dermatitis, oncology and spina bifida.	Physical Health • Fatigue • Mobility • Pain Intensity • Pain Interference • Upper Extremity Function • *Asthma Impact** • Pain Behavior • Physical Activity • Physical Stress Experiences • Strength Impact Mental Health • Anxiety • Depressive Symptoms • Anger • Cognitive Function • Life Satisfaction • Meaning and Purpose • Positive Affect • Psychological Stress Experiences Social Health • Peer relationships • Family Relationships **Italics are additional domains beyond the basic tool*
COMPUTER ADAPTIVE TEST AND SHORT PAPER FORMS AVAILABLE		
Yes, both.	Yes, both.	Yes, both and also iPad app
DEMO VERSION OR REVIEW COPIES		
https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory/pedsql-review-copies	https://www.kindl.org/english/cat-screen/demo-version/	https://www.assessmentcenter.net/ac1/Default.aspx?SID=56108DA6-2A10-475E-A030-85A13A594282

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[15] RELATED COA INSTRUMENTS—SEE APPENDIX A

PEDSQL™ [12]	KINDL®	PROMIS®
INITIAL FEEDBACK		
While PedsQL™ is currently used the most in practice, experts report that it is outdated and that the original developers of tool have since migrated to the PROMIS® framework. The PedsQL™ may, however, perform better with a broader group		PROMIS® has been tested and validated with clinical practice in mind. The PROMIS® tool could be used with other supplemental surveys/questions; however, those questions must be appropriate for the population. The PROMIS® Global 10 overlaps physical and mental health well, but is not as relevant to children with disabilities. The PROMIS® does have a subjective well-being scale.

GENERAL FEEDBACK

- The available tools are geared toward general population or children with chronic illness versus children with disabilities.
  - For kids with medical complexity and or disabilities the tools could include a scale that looks at social experience. For example: Pediatric Stigma or Neuro Qual, which is part of PROMIS®.
- Fatigue not always included in surveys but might be an element to include because of the pervasiveness of the issue.
- CMS should consider the child population being surveyed and only ask appropriate questions. For example, repeated questions related to ambulation or repeated surveys about ambulation should not be asked of a non-ambulatory population.
- Kid’s Screen was validated using a European sample. Content is much more overlapping for children with special health care needs. Kid’s Screen is still not necessarily relevant to children with medical complexity.

PARENT HEALTH

PROMIS® GLOBAL-10	STRESS INDEX FOR PARENTS OF ADOLESCENTS (SIPA – STRESS)	PARENTING STRESS INDEX (PSI – STRESS)
DESCRIPTION		
See file - [PRO-Measures-Global-Health-May-2018.pdf] The PROMIS® Global-10 is a publically available global health assessment tool that allows measurements of symptoms, functioning, and HRQOL for a wide variety of chronic diseases and conditions.	See file - [SIPA-MaryLisa-Intro.ppt] Useful for family counseling, forensic evaluations for adolescent custody, identification of dysfunctional parent-adolescent systems, prevention programs designed to reduce parental stress, and intervention and treatment planning in high stress areas.	See file - [PSI-4.pptx] The PSI™-4 is commonly used as a screening and triage measure for evaluating the parenting system and identifying issues that may lead to problems in the child's or parent's behavior. This information may be used for designing a treatment plan, for setting priorities for intervention, and/or for follow-up evaluation. Other common settings for administration of the PSI™ 4 include medical centers where children are receiving medical care, outpatient therapy settings, pediatric practices and treatment outcome monitoring.
COST		
PROMIS is available as an app for the iPad at the iTunes store (by Glinberg & Associates, Inc) https://itunes.apple.com/us/app/promis/id1039059864?mt=8 PROMIS includes a free Trial Mode that allows users to explore the app and access instruments without a time limit. Please note Trial Mode does not save data or include reports and data exports. To use PROMIS without feature restrictions users must subscribe to a 1-year auto-renewing subscription of $499.99. With the purchase of this app, users have access to other measurement systems funded by the National Institutes of Health including the	Hand score or Internet based: • Hand score kit is $179 for 25 paper administration, then $65 for 25 additional paper administrations; • Internet administration is $3 per each i-administration ($2 each use; $1 score)	Hand score, computer or Internet based: PSI™-4 hand score kit costs $262 for 25 paper administrations then $92 for 25 additional paper administrations; Computer/Internet base is $666 for software for one computer or one user for five electronic administrations; $231 for 50 additional electronic administrations; $7.50 per each i-administration ($4.50 per each i-administration use and $3 each per score)

PROMIS® GLOBAL-10	STRESS INDEX FOR PARENTS OF ADOLESCENTS (SIPA – STRESS)	PARENTING STRESS INDEX (PSI – STRESS)
PROMIS®, Neuro-QoL, TBI-QOL, SCI-QOL, SCI-FI, and ECOG. This subscription may be used on any iPad on which the NIH Toolbox app is installed, as long as the same Apple ID used for purchase is entered. After the subscription fee has been charged, the subscription cannot be cancelled.		
CREDENTIALS OF STAFF ADMINISTERING		
Self-report	B (Degree from four-year college in psychology or counseling) or S (degree certification or license to practice in physical or mental health care profession)	B (Degree from four-year college in psychology or counseling) or S (degree certification or license to practice in physical or mental health care profession)
LENGTH		
Short form has 10 items Scoring allows two four-item summary scores (Global Physical Health and Global Mental Health) that can be converted into a metric allowing comparisons to general populations.[16]	20 minutes to administer and 10 to 15 minutes to score	20 minutes Self-report inventory features 120 questions for parents and children in three domains (Hand score in five minutes or use software. Short form has 36 items in three domains taking 10 minutes to administer and five minutes to score.)
DOMAINS		
Short Form: symptoms, functioning, and HRQOL. The PROMIS® Global-10 short form consists of 10 items that assess general domains of health and functioning including overall physical health, mental health, social health, pain, fatigue and overall perceived quality of life.	• Areas include parent-focused inspection of life restrictions, relationship with spouse/partner, social alienation and incompetence/guilt. • Areas include adolescent-focused inspection of moodiness/emotional lability, social isolation/withdrawal,	Long form has three domains: • Child characteristics • Parent characteristics • Situational/ demographic life stress Short form has three domains: • Parental distress • Parent-child dysfunctional interaction

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[16] Built upon the legacy tools the SF-36 and the EQ-5D.

PROMIS® GLOBAL-10	STRESS INDEX FOR PARENTS OF ADOLESCENTS (SIPA – STRESS)	PARENTING STRESS INDEX (PSI – STRESS)
	delinquency/antisocial and failure to achieve or persevere.	• Difficult child Within the Child Domain, six subscales: • Distractibility/hyperactivity • Adaptability • Reinforces parent • Demandingness • Mood • Acceptability Evaluate sources of stress as gathered from the parent's report of child characteristics. Within the Parent Domain, seven subscales: • Competence • Isolation • Attachment • Health • Role restriction • Depression • Spouse/parenting partner relationship Measure sources of stress related to parent characteristics.
COMPUTER, ADAPTIVE TEST AND SHORT FORMS AVAILABLE		
Paper, computer and app available.	Online or paper long form.	Yes, all three are available.
AGE		
Adult survey that can be used to measure stress of the individual including stress related to parenting	Parents of adolescents (Ages 11–19)	Parents of children up to 12 years of age (PSI™-4);
SAMPLE REPORT		
See file - [ALL COMPLETE PROMIS 10 PROMIS 29 sample report.pdf]	See file - [SIPA PiC sample report.pdf]	See files - [PSI-4_Interp_PiC sample interpretive report.pdf] & [PSI-4_PiC sample report.pdf]

PROMIS® GLOBAL-10	STRESS INDEX FOR PARENTS OF ADOLESCENTS (SIPA – STRESS)	PARENTING STRESS INDEX (PSI – STRESS)
INITIAL FEEDBACK		
		PSI may be more relevant depending on CMS's goals. It is more sensitive to change as a result of interventions. It is longer than other tools and results may be more difficult to interpret.

The Caregiver Priorities (CP) tool allows parents to rank what they think is most important. The tool has not been validated in any population other than children with cerebral palsy.

Please note: The Health Related Quality of Life (HRQOL) survey is a brief survey used to assess an adult's general perception of their health. It is brief and publicly available. The HRQOL has been, since 2003, included in the Medicare Health Outcomes Survey, a measure in the National Committee for Quality Assurance Healthcare Effectiveness Data and Information Set (NCQA HEDIS).

Appendix A— Related Clinical Outcomes Assessment (COA) Instruments

- PedsQL™ Arthritis Module - Pediatric Quality of Life Inventory™ Arthritis Module
- PedsQL™ Asthma Module - Pediatric Quality of Life Inventory™ Asthma Module
- PedsQL™ Asthma Module Short Form - Pediatric Quality of Life Inventory™ Asthma Module Short Form
- PedsQL™ Brain Tumor Module - Pediatric Quality of Life Inventory™ Brain Tumor Module
- PedsQL™ Cancer Module - Pediatric Quality of Life Inventory™ Cancer Module
- PedsQL™ Cardiac Module - Pediatric Quality of Life Inventory™ Cardiac Module
- PedsQL™ Cerebral Palsy Module - Pediatric Quality of Life Inventory™ Cerebral Palsy Module
- PedsQL™ Cognitive Functioning Scale™ - Pediatric Quality of Life Inventory™ Cognitive Functioning Scale™
- PedsQL™ Diabetes Module 3.0 - Pediatric Quality of Life Inventory™ 3.0 Diabetes Module
- PedsQL™ Diabetes Module 3.2 - Pediatric Quality of Life Inventory™ 3.2 Diabetes Module
- PedsQL™ Duchenne Muscular Dystrophy Module - Pediatric Quality of Life Inventory™ Duchenne Muscular Dystrophy Module
- PedsQL™ End Stage Renal Disease Module - Pediatric Quality of Life Inventory™ End Stage Renal Disease Module
- PedsQL™ Eosinophilic Esophagitis Module - Pediatric Quality of Life Inventory™ Eosinophilic Esophagitis Module
- PedsQL™ Eosinophilic Esophagitis Symptoms Scales - Pediatric Quality of Life Inventory™ Eosinophilic Esophagitis Symptoms Scales
- PedsQL™ Epilepsy Module - Pediatric Quality of Life Inventory™ Epilepsy Module
- PedsQL™ Family Impact Module - Pediatric Quality of Life Inventory™ Family Impact Module
- PedsQL™ Family Information Form - Pediatric Quality of Life Inventory™ Family Information Form
- PedsQL™ Gastrointestinal Symptoms Module - Pediatric Quality of Life Inventory™ Gastrointestinal Symptoms Module
- PedsQL™ Gastrointestinal Symptoms Scales - Pediatric Quality of Life Inventory™ Gastrointestinal Symptoms Scales
- PedsQL™ General Well-Being Scale - Pediatric Quality of Life Inventory™ General Well-Being Scale
- PedsQL™ Generic Core Scales - Pediatric Quality of Life Inventory™ Generic Core Scales
- PedsQL™ Generic Core Scales Short Form 15 - Pediatric Quality of Life Inventory™ Generic Core Scales Short Form 15
- PedsQL™ Healthcare Satisfaction Generic Module - Pediatric Quality of Life Inventory™ Healthcare Satisfaction Generic Module
- PedsQL™ Healthcare Satisfaction Hematology/Oncology Specific Module - Pediatric Quality of Life Inventory™ Healthcare Satisfaction Hematology/Oncology
- PedsQL™ Infant Scales™ - Pediatric Quality of Life Inventory™ Infant Scales™

- PedsQL™ Multidimensional Fatigue Scale - Pediatric Quality of Life Inventory™ Multidimensional Fatigue Scale
- PedsQL™ Neurofibromatosis Module - Pediatric Quality of Life Inventory™ Neurofibromatosis Module
- PedsQL™ Neuromuscular Module - Pediatric Quality of Life Inventory™ Neuromuscular Module
- PedsQL™ Oral Health Scale™ - Pediatric Quality of Life Inventory™ Oral Health Scale™
- PedsQL™ Pediatric Pain Coping Inventory™ - Pediatric Quality of Life Inventory™ Pediatric Pain Coping Inventory™
- PedsQL™ Pediatric Pain Questionnaire™ - Pediatric Quality of Life Inventory™ Pediatric Pain Questionnaire™
- PedsQL™ Pediatric Present Functioning Visual Analogue Scales - Pediatric Quality of Life Inventory™ Pediatric Present Functioning Visual Analogue Scales
- PedsQL™ Rheumatology Module - Pediatric Quality of Life Inventory™ Rheumatology Module
- PedsQL™ Sickle Cell Disease Module - Pediatric Quality of Life Inventory™ Sickle Cell Disease Module
- PedsQL™ Stem Cell Transplant Module - Pediatric Quality of Life Inventory™ Stem Cell Transplant Module
- PedsQL™ Transplant Module - Pediatric Quality of Life Inventory™ Transplant Module

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Appendix C

CYSHCN TAP Articles and Additional Information

Articles

1. Pediatric Advance Directives: Parents’ Knowledge, Experience, and Preferences: http://pediatrics.aappublications.org/content/pediatrics/134/2/e436.full.pdf
2. Aligning Services with Needs: Characterizing the Pyramid of Complexity Tiering for Children with Chronic and Complex Conditions: https://www.lpfch.org/sites/default/files/field/publications/aligning_services_with_needs.pdf
3. Family Adjustment to Childhood Developmental Disability: A Measure of Parent Appraisal of Family Impacts: https://academic.oup.com/jpepsy/article/27/3/271/908862
4. Development of the PROMIS® Pediatric Global Health (PGH-7) Measure: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3966936/
5. State Strategies for Medicaid Quality Improvement for Children and Youth with Special Health Care Needs: https://nashp.org/wp-content/uploads/2017/11/MQM.pdf
6. Experts’ Perspectives toward a Population Health Approach for Children with Medical Complexity: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5545175/

Additional Information

1. Florida’s Title V Children and Youth with Special Health Care Needs Technical Advisory Panel Preliminary Consensus Statement: http://www.floridahealth.gov/programs-and-services/childrens-health/cms-specialty-programs/title-v-tap/_documents/title-v-tap-consensus.pdf

Tools

1. PROMIS
    a. List of Pediatric Measures: http://www.healthmeasures.net/index.php?option=com_content&view=category&layout=blog&id=114&Itemid=809
    b. Link to download actual PROMIS measure surveys: http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures
2. Parenting Stress Index (Requires a fee to download however, there are some sample reports and a presentation under the *resources* tabs in the links below)
    https://www.parinc.com/products/pkey/335

    https://www.parinc.com/Products/Pkey/333
3. PedsQL (Free license to download survey from this website): http://www.pedsql.org/pedsql12.html