

Quality of Life and Well-Being for Children and Youth With Special Health Care Needs and their Families: A Vision for the Future

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abstract

OBJECTIVES: To fulfill the promise of a life of dignity, autonomy, and independence for children and youth with special health care needs (CYSHCN) and their families, greater value must be assigned to meaningful outcomes, such as quality of life and well-being.

METHODS: Despite decades of research, programs, and measurements addressing quality of life and well-being for CYSHCN and their families, there still is no consensus on how to measure, implement, or achieve them.

RESULTS: As the US health care system strives to reach the health care goals of safe, efficient, effective, equitable, timely, and patient-centered care, youth and families must be equal partners at all levels of the health care system—from clinical decision making to designing and implementing programs and policies.

CONCLUSIONS: The health care system must systematically measure the priorities of CYSHCN and their families. It also must incorporate data on quality of life and well-being when developing services, supports, and systems that help CYSHCN and their families to flourish rather than hindering them.

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Disability is a natural part of the human experience and in no way diminishes the right of individuals to flourish, live full well-rounded lives, and participate in or contribute to society.¹ Federal laws protect these rights,^{2,3} but the promise of such a holistic vision throughout the life course for children and youth with special health care needs (CYSHCN) and their families remains unfulfilled. In the 2018 to 2019 National Survey of Children's Health (NSCH), caregivers reported a significantly lower quality of life for CYSHCN than children without special health care needs, including such critical items as more missed school days, difficulty making friends, and lower participation in organized activities (Table 1).

As the US health care system strives to achieve the health care goals of safe, efficient, effective, equitable, timely, and patient-centered care,⁴ it must measure indicators of access to health services and functional outcomes. However, it is not sufficient to promote the health of CYSHCN without also considering the many components that contribute to quality of life and well-being. These could include protective factors such as socializing with friends and participating in accessible activities, or risk factors such as missing school for medical appointments or experiencing bullying. For the health care system to promote dignity, autonomy, and independence for CYSHCN and their families, and achieve its goals, greater value must be assigned to well-being and quality of life, as defined by individuals and families with lived experience.^{5,6} Youth with special health care needs and their families must be equal partners at all levels of the health care system, from clinical decision making to designing and implementing programs and policies. Data on

quality of life and well-being gathered from them can be used to develop services that promote rather than hinder a life of quality for CYSHCN and their families.

A Blueprint for Change: Guiding Principles for Advancing the System of Services for CYSHCN and their Families (hereafter referred to as *Blueprint for Change*) outlines principles and strategies that can be implemented to achieve a strong system of services for CYSHCN. The *Blueprint for Change* recommends strategies to measure well-being and quality of life that can transform systems to improve quality and access to needed patient and family-centered services. Such improvements could lead to a future in which "service systems prioritize quality of life and support the flourishing of CYSHCN and their families."⁷ Prioritizing well-being and quality of life outcomes in health care systems places value on measuring what matters most to CYSHCN, the whole person (hereinafter referred to as "whole child or whole family") (ie, physical, mental, social, intellectual and spiritual needs), not just a diagnosis.⁸

Well-Being and Quality of Life

The concepts of well-being and quality of life are interdependent and influenced by multiple factors, including sense of community and social integration; socioeconomic and employment status; and self-perceived physical, cognitive, emotional, and social functioning.⁹⁻¹³ A widely cited definition, developed by the World Health Organization, defines quality of life as "an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."¹⁴

In health care literature, the broad concept of quality of life often is used interchangeably with its specific dimensions, such as health-related quality of life and functioning, disability, and health (FDH).^{15,16} The Centers for Disease Control and Prevention defines health-related quality of life as "an individual's or group's perceived physical and mental health over time," whereas FDH "comprises the biopsychosocial components and interactions among body structures and function, and activities and participation in the context of environment and personal factors."^{17,18}

Measurement

In part, because of the conceptual complexity inherent in the concepts of quality of life and well-being, there is no universally accepted gold standard tool for measurement.¹⁹ Historically, quality of life and well-being measures were not developed in collaboration with individuals with lived experience, resulting in a narrow set of indicators, often designed with an ableist,²⁰ Western, White, and adult-focused bias that inaccurately assesses the diverse experiences of CYSHCN and their families.^{15,16} Existing tools to measure quality of life have limitations. For example, instruments that assess health-related quality of life tend to be generic, such as the PedsQL²¹ and KIDSCREEN,²² or condition specific, covering conditions such as asthma, diabetes, and oro-facial disorders.²³ These measures fail to capture key aspects of a full life that support flourishing, such as the spirituality, relationships, values and culture of children and youth with disabilities and/or special health care needs. Even though the World Health Organization International Classification of Functioning,

TABLE 1 Quality of Life Indicators, by Special Health Care Need Status, 2018 and 2019

Indicators	Children and Youth With Special Health Care Needs	Children and Youth Without Special Health Care Needs
Child level indicators	%	%
Flourishing composite (6 mo–5 y) ^a	68.3	85.4
Child usually or always shows affection or tenderness with parent (6 mo–5 y)	93.1	97.8
Child usually or always bounces back when things don't go his or her way (6 mo–5 y)	78.7	91.2
Child usually or always shows curiosity in learning new things (6 mo–5 y)	88.5	95.8
Child usually or always smiles and laughs (6 mo–5 y)	96.0	99.3
Flourishing composite (6–17 y) ^b	44.5	73.1
Child usually or always shows curiosity in learning new things (6–17 y)	80.3	92.5
Child usually or always finishes tasks (6–17 y)	66.6	89.9
Child usually or always stays calm and in control, when faced with a challenge (6–17 y)	54.1	83.6
Other child QoL indicators (6–17 y)		
Child missed >6 school days in the past 12 mo (6–17 y)	23.9	6.9
Child was bullied at least 1 to 2 times a month (6–17 y)	28.2	10.9
Child has a lot of difficulty making and keeping friends (6–17 y)	15.0	1.5
Child participated in at least 1 organized activity or lesson (6–17 y)	74.3	81.5
Family level indicators		
Parent reports feeling aggravated by parenting ^c	16.7	2.3
Parent reports coping very well with the demands of childrearing	52.3	65.5
Parent reports having to change job due to childcare	16.8	8.3
Parent reports spending 5 or more hours per week coordinating and/or providing health care	24.1	9.9
Parent reports family resilience behaviors (composite measure) ^d	76.2	83.7
Neighborhood level indicators		
Child lives in a supportive neighborhood ^e	48.2	56.6
Child lives in a safe neighborhood ^f	59.0	65.8
Child attends a safe school ^g	63.9	72.0
Child lives in a neighborhood with amenities ^h	36.3	39.2

^a Response: Child usually or always displays all 4 flourishing items.

^b Response: Child usually or always displays all 3 flourishing items.

^c Response: Parent usually or always feels their child is much harder to care for than other children or is usually or always bothered a lot by their child's behavior or usually or always feels angry with their child.

^d Response: Family most of the time or all of the time talks together about what to do, works together to solve problems, knows they have strengths to draw on, and stays hopeful in difficult times.

^e Response: Parent definitely agrees to at least 1 of the following items and somewhat agrees or definitely agrees to the other 2 items: people in their neighborhood help each other out, watch out for each other's children, and know where to go for help in their community.

^f Response: Parent definitely agrees that their child lives in a safe neighborhood.

^g Response: Parent definitely agrees that their child attends a safe school.

^h Response: Child's neighborhood has parks, recreation centers, sidewalks, and libraries.

Disability and Health offers a more expansive view of childhood disability, its use too often is focused narrowly on functional ability and not necessarily correlated with quality of life.²⁴ The lack of consensus on essential measurement characteristics restricts their use and adoption in applied clinical settings.^{14,25} As health care systems continue to incentivize quality care, it is imperative to focus on outcomes that measure quality of life and well-being based on the needs of CYSHCN and their families. Although undoubtedly important for CYSHCN, clinical care should not be delivered in a vacuum;

instead, it must be integrated with the other meaningful components of each child's and family's life.

The Disability Context of Quality of Life

In the mid-20th century, disability rights advocates fought to change public and professional perspectives on disability. They promoted strategies to eliminate societal barriers and maximize potential for individuals with disabilities, culminating in federal laws such as the Individuals with Disabilities Education Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act.^{2,3,26} Despite this progress, health care

professionals—whether intentionally or not—continue to demonstrate bias in their attitudes toward persons with disabilities, also known as ableism: more than 80% of physicians in a recent study perceived a worse quality of life for people with disabilities, and only 18% strongly agreed that people with disabilities are treated unfairly in the health care system.²⁷

Families have a different perspective; they may acknowledge that their lives are different and full of challenges, but they also describe the wonder and joy their CYSHCN bring to their lives.²⁸ The focus of many well-meaning professionals on

“fixing” people with disabilities misses this concept. As a result, health care professionals may limit their vision of how they might better serve these children and possibly overlook opportunities to eliminate social, attitudinal, and environmental barriers to improving quality of life and well-being for CYSHCN and their families.

Quality in health care has often been measured using deficit-based indicators, such as mortality and the presence of physical or cognitive impairments.^{15,16,29} For example, quality adjusted life years is a foundational metric of cost-effectiveness used by researchers, the pharmaceutical industry, and policymakers; it lowers the value of a year of treatment by the perceived degree to which a disability or illness affects quality of life during that year.^{30,31} This approach to measuring cost-effectiveness systematically devalues the impact of treatment on individuals with disabilities and demonstrates an historical pattern of discrimination toward children and other people with disabilities.^{32,33}

Family or Caregiver Burden Does Not Accurately Measure Quality of Life

Some quality measures focus on identifying challenges families face, often referred to as the “caregiving burden,” when navigating dysfunctional, bureaucratic, and fragmented services that can affect access and experiences of care. Many families reject the characterization of burden because it reflects negatively on their child and caregiving. It also obscures the reality that many of these problems do not originate within families but are created by inadequate and unresponsive systems.^{4,34–36,37} When health care systems use such measures, interventions may be more likely to focus on identifying the problem or alleviating individual

family stressors rather than redesigning systems to provide care for the whole child and family across the life course, to promote and not hinder quality of life.³⁸ The data in Table 1 indicate that 52% of CYSHCN have families or caregivers who report coping very well with the demands of childrearing. Yet, this is still less than the 65.5% of non-CYSHCN with families or caregivers who report coping well.³⁹ Perhaps this difference reflects the added demands of a fragmented service system and/or lack of services, resources, or support for families of CYSHCN.

Measuring What Matters to CYSHCN and Families

As demonstrated in Table 1, the NSCH has documented disparities in quality of life and well-being for CYSHCN using indicators such as number of school absences, a child’s ability to make and keep friends, and living in a supportive neighborhood. However, more research is needed to learn about the role of quality of life and well-being in achieving health outcomes and how best to measure what matters to CYSHCN and families so health care systems can implement policies, services, and supports that are more responsive to their needs.

Existing health-related quality of life or FDH measurement tools, while imperfect, are not used systematically by health care systems. Additionally, measures such as the Healthcare Effectiveness Data Information Set⁴⁰ or the Medicaid Core Set,⁴¹ which are widely used—with financial consequences for insurers and government agencies that do not meet certain metrics—do not address any dimensions of well-being or quality of life. Instead, they focus on access and screening. Rewarding large health care systems for improving children’s quality of

life and well-being in addition to clinical outcomes might provide more incentives for cross-systems integration to occur at the local, state, and national levels.

Health care systems should prioritize measuring quality of life and well-being for all aspects of a child’s life, even those outside of clinical care. Focusing on outcomes measured only by a health-related quality of life tool ignores and fails to capture other key concepts, such as autonomy, dignity, independence, spirituality, culture, relationships, coping skills, and the quality of caregiving.^{10,42} Differentiating between overall quality of life and health-related quality of life is a critical step in developing systems of services that foster dignity, autonomy, and flourishing for CYSHCN and their families.¹

Measuring what is meaningful to CYSHCN and their families is best achieved through partnership with them at the practice and systems levels. Partnership at the practice level can lead to authentic shared decision making and planning that is responsive to and reflective of the whole child and family and their priorities.⁴³ Partnership at the systems level, which values experienced youth and family leaders as public health professionals, can lead to research, development of measures, and services that meet the needs of CYSHCN and families.⁴³ A number of promising initiatives addressing these challenges are found below.

Integrating Quality of Life and Well-Being Measures at the State Level

In 2018, the Florida Surgeon General created the Title V Children and Youth with Special Health Care Needs Technical Advisory Panel to produce a report on best practices focusing on quality care and health outcomes. The panel, comprising youth, families, pediatric

organizations, payors, and pediatricians, produced Recommendations for Quality of Life Outcomes for Children and Youth with Special Health Care Needs,⁴⁴ which strongly supported measuring family and child well-being and quality of life. The panel noted that “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 report highlights how existing instruments and measures can be integrated and standardized.⁴⁴ Since publication of the report, more than 44 000 CYSHCN have enrolled in a Florida managed care plan modeled on Title V principles and were assessed using at least 2 measures of quality of life, with overall improvement in several categories reported (Jeffrey Brosco, MD, PhD, e-mail communication, September 2021). This experience provides an example for other states that are considering making measurement of quality of life and well-being for families a priority.

Palliative Care as a Whole Child Approach to Care

Palliative care, although often misunderstood and underused, is perhaps the most well-known example of an approach to health care designed explicitly to improve the quality of life of CYSHCN and their families. Its key principles are to relieve suffering (eg, pain and psychological, social, practical, and spiritual suffering), improve quality of life (both for the child and the

family), facilitate informed decision making, and coordinate care among providers and across systems.^{45,46} This holistic approach operationalizes key components of family-centered care. Notably, families report the following as the 3 most valued aspects of palliative care services: management of symptoms, provision of psychological support for their child, and communication and coordination across multiple providers and systems.⁴⁷

Because of a variety of factors, including lack of provider education and difficulty in obtaining insurance coverage, many CYSHCN and their families are unable to routinely access palliative care outside of the hospital setting. However, medical homes and other primary care settings can integrate the key principles of palliative care (ie, primary palliative care) into their models; alternatively, it can also be delivered as a specialty service.⁴⁸ To increase access to limited specialty palliative care, several states have used Medicaid state plan amendments and waivers.⁴⁹ In response to an increasing demand for access to palliative care for all CYSHCN and families, the National Pediatric Palliative Care Task Force convened in 2021 to formulate strategies for expanding access and awareness, improving financing mechanisms, and meeting this growing demand for pediatric palliative care.⁵⁰

Coordination and Collaboration Across Systems of Services for CYSHCN

CYSHCN well-being is strongly influenced by external factors, including school and other social environments⁵¹; however, integration of health and other social systems and supports is often siloed by bureaucracy and other barriers, such as lack of data sharing and financing.⁵² Telehealth offers a

strategy to bridge existing gaps in coordination between state Medicaid programs and school systems.⁵³ Thirty-one states have published guidance allowing Medicaid reimbursement for school-based telehealth services. For example, in North Carolina, families could not use Medicaid waivers for home health services delivered while CYSHCN were engaged in virtual learning because both services rely on federal funding. Recognizing the role both services play in promoting health and quality of life during the COVID-19 pandemic, North Carolina Health and Human Services worked with the Centers for Medicare & Medicaid Services to develop North Carolina’s new Appendix K Waiver, allowing CYSHCN to use home health and virtual or in-person educational services simultaneously.⁵³

Recommendations

The COVID-19 pandemic has forced our fragmented health care system to rapidly adopt previously unimaginable changes. Delivering care in a system that promotes well-being and quality of life merits the same level of urgency and innovation. Reorienting the health care system to equally prioritize child and family well-being and quality of life as well as clinical outcomes will require action at the research, practice, and policy levels.

Research

In partnership with CYSHCN and their families, health care systems should support developing a family-centered research agenda to identify and test effective measures for well-being and quality of life, including:

1. Develop well-being and quality of life measures that reflect the diverse needs CYSHCN and their families beyond their diagnosis and interaction with the health care system and

integrate services and supports that are meaningful to children and families across the life course.

2. Develop “core outcome sets” for conditions that affect CYSHCN.^{54,55}
3. Identify how ableism manifests in pediatric health care delivery and how perceptions of disability can influence the care provided to CYSHCN.

Policy

Policy makers and those in positions to influence systems change must partner with youth and families to develop and implement federal and state policies supporting care delivery that values, prioritizes, and promotes the well-being and quality of life of the whole child and family across the life course.

1. Policies for federal and state programs serving CYSHCN should incorporate measurement of well-being and quality of life, as well as family-professional partnership, as components of all care delivery, quality improvement projects, research, and systems transformations.
2. Policies should be developed to support the integration of well-being and quality-of-life measures into instruments such as NSCH, Healthcare Effectiveness Data Information Set, and the Medicaid Core Set, and align measures across the multiple systems of services for CYSHCN.
3. Policies should mandate the development of training curricula in partnership with patient and family faculty. These curricula should provide education about disability, family-centered care, and the principles of palliative care, and promote their inclusion as core components of health professional and continuing education and training at all levels.

Practice

In partnership with CYSHCN and families, health care systems and practitioners should develop, identify, and promote models of care delivery and other services that prioritize and integrate well-being and quality of life across the life course.

1. Health care systems should promote approaches to applying principles used in palliative care throughout care delivery for CYSHCN.
2. Health care systems should promote tools, such as care mapping, to facilitate shared decision making and ensure that quality of life and the needs of CYSHCN and their families are discussed in a meaningful way and integrated into health care services, and that care is coordinated across the entire ecosystem of child and family life.

CONCLUSIONS

Elevating the importance of quality of life and well-being outcomes requires a reimagining of the traditional system of care. CYSHCN and their families ultimately are the experts in defining optimal health for themselves. This view of health encompasses factors beyond physical health outcomes to include social connections, educational opportunities, recreation, and spirituality. Measuring and attaining a health care system that values quality of life and well-being for CYSHCN and their families requires change at both the system and individual levels; such change can be achieved only in partnership with CYSHCN, families, providers, and local, state, and federal governments.

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ABBREVIATIONS

CYSHCN: children and youth with special health care needs
FDH: functioning, disability, and health
NSCH: National Survey of Children’s Health

REFERENCES

1. Developmental Disabilities Assistance and Bill of Rights Act of 2000 (2000 – H.R. 4920)
2. Americans with Disabilities Act of 1990. Public Law 101-336 § 1
3. Individuals with Disabilities Education Act of 2004. 20 U.S.C. § 1400, et
4. Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health Care System for the 21st Century*. Washington, D.C.: National Academies Press; 2001
5. Cohen E, Berry JG, Sanders L, Schor EL, Wise PH. Status complexus? the emergence of pediatric complex care. *Pediatrics*. 2018;141(suppl 3):S202–S211
6. Perrin JM. Innovative health care financing strategies for children and youth with special health care needs. *Pediatrics*. 2017;139(suppl 2):S85–S88
7. McLellan SE, Mann MY, Scott JA, Brown TW. A blueprint for change: guiding principles for a system of services for children and youth with special health care needs and their families. *Pediatrics*. 2022;149(suppl 7):e2021056150C
8. National Center for Complementary and Integrative Health. Whole person health: what you need to know. Available at: <https://www.nccih.nih.gov/health/whole-person-health-what-you-need-to-know>. Accessed October 8, 2021
9. Garona C, Silva N, Crespo C, Canavarró MC. Caregiving burden and parent-child quality of life outcomes in neurodevelopmental conditions: the mediating role of behavioral disengagement. *J Clin Psychol Med Settings*. 2014;21(4):320–328

10. Whitmore KE, Snethen J. Respite care services for children with special health-care needs: parental perceptions. *J Spec Pediatr Nurs*. 2018;23(3):e12217
11. Algood C, Davis AM. Inequities in family quality of life for African-American families raising children with disabilities. *Soc Work Public Health*. 2019;34(1):102–112
12. Bornstein MH, Davidson L, Keyes CLM, Moore KA, eds. *Crosscurrents in Contemporary Psychology. Well-Being: Positive Development across the Life Course*. Mahwah, NJ: Lawrence Erlbaum Associates Publishers; 2003
13. Barnert ES, Collier RJ, Nelson BB, et al. A healthy life for a child with medical complexity: 10 domains for conceptualizing health. *Pediatrics*. 2018;142(3):e20180779
14. The World Health Organization. WHOQOL: measuring quality of life. Available at: https://cdn.ymaws.com/www.safestates.org/resource/resmgr/connections_lab/glossary_citation/WHO__WHOQOL_Measuring_Qualit.pdf. Accessed July 7, 2021
15. Wallander JL, Koot HM. Quality of life in children: A critical examination of concepts, approaches, issues, and future directions. *Clin Psychol Rev*. 2016;45:131–143
16. Vente T. How do you focus on quality of life when kids cannot go to school or outside? *Curr Pediatr Rep*. 2021;9(2):37–45
17. Centers for Disease Control and Prevention. Health-related quality of life (HRQOL). Available at: <https://www.cdc.gov/hrqol/wellbeing.htm#three>. Accessed September 8, 2021
18. World Health Organization. International classification of functioning, disability and health (ICF). Available at: <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>. Accessed September 8, 2021
19. National Academy for State Health Policy. The national standards for children and youth with special health care needs: a compendium of national data and quality measure sets. Available at: <https://www.nashp.org/national-standards-for-cyshcn-measures-compendium/>. Accessed September 8, 2021
20. Bogart KR, Dunn DS. Ableism special issue introduction. *J Soc Issues*. 2019;75(3):650–664
21. Varni JW. Pediatric quality of life inventory measurement model. Available at: <https://www.pedsql.org/>. Accessed September 6, 2021
22. KIDSCREEN. Health-related quality of life questionnaire for children and adolescents aged from 8 to 18 years. Available at: <https://www.kidscreen.org/english/questionnaires/>. Accessed September 8, 2021
23. Chow MY, Morrow AM, Cooper Robbins SC, Leask J. Condition-specific quality of life questionnaires for caregivers of children with pediatric conditions: a systematic review. *Qual Life Res*. 2013;22(8):2183–2200
24. Rosenbaum P, Gorter JW. The ‘F-words’ in childhood disability: I swear this is how we should think! *Child Care Health Dev*. 2012;38(4):457–463
25. Anderson B, Beckett J, Wells N, Comeau M. The eye of the beholder: a discussion of value and quality from the perspective of families of children and youth with special health care needs. *Pediatrics*. 2017;139(suppl 2):S99–S108
26. Nondiscrimination on the Basis of Handicap in Programs or Activities Receiving Federal Financial Assistance. Section 504 of the Rehabilitation Act of 1973, 34 C.F.R. part 104. Available at: <https://www2.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>. Accessed September 6, 2021
27. Lezzoni L, Rao S, Ressalam J, Bolcic-Jankovic D, Agaronnik N. Physicians’ perceptions of people with disability and their health care. *Health Aff. (Millwood)* 2021;40(2):297–306
28. Hossain M, Seifert B, Christensen A, Shattuck P. Meeting proceedings: children and youth with special health care needs (CYSHCN) summit series. December 2020; Washington, DC: Mathematica
29. Brosco JP. The early history of the infant mortality rate in America: “A reflection upon the past and a prophecy of the future”. *Pediatrics*. 1999;103(2):478–485
30. National Council on Disability. Quality adjusted life years and the devaluation of life with disability. Available at: https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf. Accessed September 8, 2021
31. Griebisch I, Coast J, Brown J. Quality-adjusted life-years lack quality in pediatric care: a critical review of published cost-utility studies in child health. *Pediatrics*. 2005;115(5):e600–e614
32. National Disability Rights Network. Devaluing people with disabilities: medical procedures that violate civil rights. Available at: <https://www.ndrn.org/wp-content/uploads/2012/05/Devaluing-People-with-Disabilities.pdf>. Accessed September 8, 2021
33. Gunther DF, Diekema DS. Attenuating growth in children with profound developmental disability: a new approach to an old dilemma. *Arch Pediatr Adolesc Med*. 2006;160(10):1013–1017
34. Yantzi N, Rosenberg MW, Burke SO, Harrison MB. The impacts of distance to hospital on families with a child with a chronic condition. *Soc Sci Med*. 2001;52(12):1777–1791
35. Chisholm J. The context, content and consequences of mothering a child with disabilities. *Axone*. 2000;22(2):22–28
36. Comeau M; Lucile Packard Foundation for Children’s Health. Family burden and medical complexity: wrestling with the meaning and impact of commonly used terms. Available at: https://www.lpfch.org/sites/default/files/field/publications/family_burden_and_medical_complexity_by_meg_comeau_06.2019.pdf. Accessed September 8, 2021
37. Leo G. 10 thinks: a message from parents, don’t forget the bubbles. Available at: <https://doi.org/10.31440/DFTB.16103>. Accessed September 8, 2021
38. Carosella A, Snyder A, Ward E. What parents of children with complex medical conditions want their child’s physicians to understand. *JAMA Pediatr*. 2018;172(4):315–316
39. Stille CJ. Better health service use for families of children with special health care needs. *Pediatrics*. 2020;145(2):e20193694
40. NCQA. HEDIS and performance measurement. Available at: <https://www.ncqa.org/hedis/>. Accessed July 5, 2021
41. Centers for Medicare & Medicaid Services. Adult and child health care quality measures. Available at: <https://www.medicare.gov/medicaid/quality-of-care/performance-measurement/adult-and>

- child-health-care-quality-measures/index.html. Accessed July 5, 2021
42. Krahn GL, Putnam M, Drum CE, Powers L. Disabilities and health: toward a national agenda for research. *J Disabil Policy Stud.* 2006;17(1):18–27
 43. Hossain M, Alvarez C, Shattuck P, Christensen A, Zickafoose J. *Targeted Environmental Scan Report: Children and Youth with Special Health Care Needs (CYSHCN) National Summit.* Washington, DC: Mathematica; 2021
 44. Florida Health. Recommendations for quality of life outcomes for children and youth with special health care needs, prepared by the Title V Children and Youth with Special Health Care Needs Technical Advisory Panel. Available at: www.floridahealth.gov/programs-and-services/childrens-health/cms-specialty-programs/title-v-tap/_documents/CYSHCN-Quality-TAP-Report-010819-to-DOH-Final.pdf. Accessed September 8, 2021
 45. Center to Advance Palliative Care. The case for community-based palliative care: a new paradigm for improving serious illness care. Available at: [file:///C:/Users/mmorrison/Downloads/the-case-for-community-based-palliative-care%20\(1\).pdf](file:///C:/Users/mmorrison/Downloads/the-case-for-community-based-palliative-care%20(1).pdf). Accessed September 8, 2021
 46. National Hospice and Palliative Care Organization. Pediatric concurrent care. Available at: https://www.nhpc.org/wp-content/uploads/2019/04/Continuum_Briefing.pdf. Accessed September 8, 2021
 47. Boyden JY, Ersek M, Deatrck JA, et al. What do parents value regarding pediatric palliative care and hospice care in the home setting? *J Pain Symptom Manage.* 2021;61(1):12–23
 48. Sreedhar CK, Friebert S, Kraft, C. Primary palliative care: skills for all clinicians. *Curr Prob Pediatr Adolesc Health Care,* 2020;50(6):100814
 49. National Academy for State Health Policy (NASHP). Recent state actions that support and expand palliative care. Available at: <https://www.nashp.org/states-increasingly-support-palliative-care-for-serious-illness-through-laws-and-appropriations/>. Accessed September 8, 2021
 50. Pediatric Palliative Care Task Force. National coalition for hospice and palliative care. Available at: <https://www.nationalcoalitionhpc.org/pediatric/>. Accessed September 8, 2021
 51. Mattson G, Kuo DZ; Committee on Psychosocial Aspects of Child and Family Health; Council of Children with Disabilities. Psychosocial Factors in children and youth with special health care needs and their families. *Pediatrics.* 2019;143(1):e20183171
 52. Fine A, Kotelchuck M, Adess N, Pies C. *Policy Brief. A New Agenda for MCH Policy and Programs: Integrating a Life Course Perspective.* Martinez, CA: Contra Costa Health Services; 2009
 53. Girmash E; NASHP. State strategies to support the health needs of children with special needs in schools during COVID-19. Available at: <https://www.nashp.org/state-strategies-to-support-the-health-needs-of-children-with-special-needs-in-schools-during-covid-19/>. Accessed September 8, 2021
 54. Brosco JP, Hinton CF. Following patients with inborn errors of metabolism: what do we value and how do we know? *Pediatrics.* 2021;148(2):e2021051020
 55. Pugliese M, Tingley K, Chow A, et al; Canadian Inherited Metabolic Diseases Research Network. Core outcome sets for medium-chain Acyl-CoA dehydrogenase deficiency and phenylketonuria. *Pediatrics.* 2021;148(2):e2020037747