

Research on Family Health and Children and Youth With Special Health Care Needs



Karen A. Kuhlthau, PhD; Stefanie G. Ames, MD, MS; Allysa Ware, MSW; Clarissa G. Hoover, MPH; Nora Wells, MEd; Charlene Shelton, RN, MA, MPA, PhD

From the Department of Pediatrics, Harvard Medical School and Massachusetts General Hospital (KA Kuhlthau), Boston, Mass; Critical Care Medicine, Department of Pediatrics, University of Utah School of Medicine (SG Ames), Salt Lake City, Utah; Family Voices (A Ware, CG Hoover, and N Wells), Lexington, Mass; and Department of Pediatrics, ACCORDS, University of Colorado School of Medicine (C Shelton), Aurora, Colo

The authors have no conflicts of interest to disclose.

Address correspondence to Karen A. Kuhlthau, PhD, Department of Pediatrics, Harvard Medical School and Massachusetts General Hospital, 125 Nashua St, 8th Floor, Boston, MA 02114 (e-mail: kkuhlthau@mgh.harvard.edu, kkuhlthau@partners.org).

Received for publication March 2, 2021; accepted July 23, 2021.

ABSTRACT

Families of children and youth with special health care needs (CYSHCN) can face challenges with regard to health and well-being. Health systems are designed to support CYSHCN but do not often consider the health and well-being of their family. Despite a growing body of literature, substantial gaps remain in our understanding of the impact of caregiving on family health and well-being and mechanisms of supporting families. In order to better understand and address these gaps, a national CYSHCN network developed a national research agenda to prioritize key areas of insufficient understanding of health and well-being for families of CYSHCN. Questions identified by the research agenda include: 1) How can family resiliency and adaptability be measured and improved? 2) How can we better assess family mental health needs and implement appropriate interventions? 3) What is the impact of family health on CYSHCN health outcomes? This paper describes a review of

what is currently known regarding health for families of CYSHCN, gaps in the literature focused on the research agenda questions, and recommendations for future research. Based on the research agenda and current state of research for family health of CYSHCN, the authors recommend focusing on resiliency and adaptability as outcomes, using implementation science to address mental health concerns of family members and to further assess the impact of family health on health outcomes of CYSHCN. In addition, research should have a special focus on diverse populations of families and consider these questions in the context of different family structures.

KEYWORDS: caregiver health; families; family health; research agenda; stakeholder engagement

ACADEMIC PEDIATRICS 2022;22:S22–S27

WHAT'S NEW

This paper reports on the consensus research priorities for families of children and youth with special health care needs.

IN ORDER TO prioritize research likely to have the greatest impact, the children and youth with special health care needs (CYSHCN) research network conducted a consensus-based process, the RAND appropriateness method (RAM), to identify research priorities for CYSHCN.¹ This structured process with key family and professional stakeholders resulted in the identification of 9 themes with key research areas for focus in future work. This paper outlines identified gaps in research related to one of these 9 areas, family health in families with CYSHCN. Overall, the consideration of family health in studies of CYSHCN is understudied. Understanding the constellation of interconnected factors that drive family health and well-being is important to ensuring that CYSHCN flourish and thrive.

In this paper, family includes individuals based on marriage, legal ties, blood, cohabitation, and other social ties.

Family health is a dynamic state that emerges from the intersection of the health and needs of each family member and of their access to the supports and resources they need to be healthy. Family health is greater than the sum of its parts and is an important determinant of child health.

WHAT IS KNOWN AND CURRENT KNOWLEDGE GAPS

While there is a large body of research on family health for all families, there is a smaller body of work specifically related to families of CYSHCN. Much of the work related to families of CYSHCN has described challenges in family physical and emotional health, family function, and caregiver strain. Other recent work has focused on family resilience, adaptation to adverse circumstances, and promotion of caregiver well-being through family-centered care and caregiving skills. Studies commonly focus on primary caregivers who are most often parents but sometimes grandparents or other guardians. Some literature has expanded to also evaluate the health and well-

being of siblings. A brief overview of current literature is described below.

One area of family health research has focused on understanding family physical health. Studies report that physical health in caregivers of CYSHCN is worse than others.² Challenges in physical health reported in studies of families of CYSHCN include health problems related to physical strain and demands of caregiving as well as chronic stress and its impacts on physical health.³ Many families are at risk for poor, interrupted sleep, which may contribute to physical strain and illness.⁴ A focus area of investigation has been the association of caregiving stress and neuroendocrine dysfunction, elevated systemic inflammation, and poor immune response among the parents of CYSHCN, which may be associated with poor health outcomes.^{5,6} Lack of respite care can certainly contribute to physical and mental fatigue.⁷ In addition to the literature on parents and other primary caregivers, siblings are at risk for illness and poor health.⁸

Other research seeks to understand the emotional and psychological health of family members. Concerns regarding medical trauma and post-traumatic stress disorder from a child's illness are discussed.⁹ Parents have been noted to have higher rates of anxiety and depression than the general population.¹⁰ Parents who report having significant and undersupported care responsibilities for their child may experience caregiver strain, which contributes to poor quality of life.^{3,11} As with physical demands, the lack of respite care furthers caregiver mental and emotional fatigue.⁷ In addition, siblings of CYSHCN have been reported to have an increased risk of behavioral and mental health difficulties and poor quality of life but also form well-developed coping skills and build strong social support systems.¹²

Caregiving activities may limit a family member's ability to work and thus impact family finances. Parents report inadequate family leave, inability to pursue employment, and missed work hours, all leading to forgone earnings.¹³ High health care costs, high out-of-pocket expenses, and high rates of underinsurance contribute to high rates of financial difficulties that impact family well-being, family function, and distress.¹⁴ These financial burdens may contribute to housing instability and food insecurity, both of which have been reported to be higher in families of CYSHCN.^{15,16} These financial issues likely contribute to the elevated stress levels noted above and are experienced at greater levels in families of CYSHCN than among other families.

While families of CYSHCN face challenges with regard to their health and well-being, many families are thriving and flourishing.¹⁷ Promotion and further understanding of factors associated with family resilience, adaptation, and flourishing are becoming increasingly important in CYSHCN research.^{18,19} New research focused on interventions to improve health and well-being for families of CYSHCN highlights ways that children and their families flourish, and can promote approaches that foster resilience.²⁰ Health system structures such as advancement of the family-centered medical home and

enhanced care coordination are associated with fewer unmet needs and improved family functioning.²¹ These structures can help improve families' partnership in their care by providing consistent support, helping them act on their concerns, and improving access to needed services. Recent work has also evaluated mechanisms to increase internal supports that enhance parental and family coping skills and problem solving through peer support and engagement, educational efforts, and specific competency training.^{22,23}

Although there is a growing body of research focusing on families of CYSHCN, there remain significant gaps in the literature. Recognizing and addressing these gaps will be crucial to further advances in family health. Below we highlight 3 overarching research questions.

HOW CAN WE BETTER UNDERSTAND WHAT HELPS FAMILIES OF CYSHCN FLOURISH, BE RESILIENT AND ADAPT?

While families face many challenges, current literature on families of CYSHCN is limited. Overall, there is a lack of well-developed literature focused on the evaluation of well-being and aspects related to flourishing, resiliency, and adaptability specific to families of CYSHCN. Adaptability refers to the accommodative coping that can occur in families and individuals with chronic illness.²⁴ Resiliency is a related multidimensional construct that refers to the ability to maintain positive adaptation and effective functioning when faced with stressors.²⁵ Flourishing is a concept of well-being and includes domains such as connection, engagement, relationships, and self-worth that can occur regardless of illness and stress.¹⁸ The complexity of these multifactorial and multidimensional constructs and significant variation in family needs and experiences for families of CYSHCN lead to challenges in development, standardization, and validation of screening or measurement tools. Continued work on valid, reliable standard assessments is needed. Consistent use of common measures promotes comparison of studies of family health and evaluations of interventions to improve it. Development and validation of assessment tools specific for the evaluation of health and well-being of families CYSHCN are necessary.

HOW CAN WE BETTER ASSESS FAMILY MENTAL HEALTH NEEDS AND IMPLEMENT APPROPRIATE INTERVENTIONS?

Although a number of studies have identified family members of CYSHCN at high risk for mental health challenges such as depression, anxiety, and caregiver strain, there is a paucity of literature showing effective implementation and sustainability of universal family mental health screening and implementation of programs to effectively address these family health needs.²⁶ There is also a poor understanding of factors impacting family mental health and ways they can be moderated. In addition, more research is needed to identify optimal ways to support caregiver self-care and improve the family resiliency specifically for families of CYSHCN. Research in other populations such as caregivers of patients with dementia or cancer have demonstrated the utility of

respite care, caregiver skill training, and mindfulness-based stress reduction.^{27,28} Families of CYSHCN may face different stressors, physical demands, emotional challenges, and caregiving dynamics from caregivers of adult patients. In addition, their caregiving roles often span longer durations and therefore may place unique strain on caregivers over time. Research focused specifically on systematic identification of mental health concerns and sustainable, effective interventions in families of CYSHCN is needed.

WHAT IS THE IMPACT OF POOR FAMILY HEALTH ON CYSHCN HEALTH OUTCOMES?

Family health and well-being may also contribute to CYSHCN use of health care and health outcomes; however, this area has not been adequately explored. Family characteristics such as parental employment and insurance status are associated with delayed or inadequate care, which can contribute to poor health outcomes for CYSHCN.²⁹ Research focusing on unmet health care needs, family financial strain, and poor child health outcomes tends to focus on a limited array of family variables such as household income or insurance status.³⁰ Specific research about the availability and accessibility of needed services for families of CYSHCN and what factors help families to access needed services might consider a wider range of possible relationships between family and CYSHCN health.

KEY ADDITIONAL RESEARCH GAPS

INCLUSION OF DIVERSE FAMILIES IN RESEARCH AND THE IMPACT OF ADDING FAMILY MEMBERS TO THE RESEARCH TEAM OR STAKEHOLDER PANELS

Current research lacks emphasis on African American, Latinx, Asian, and other racial/ethnic groups, specific cultural groups, diverse family types (eg, kinship, adoptive, foster relationships), low-income families, and families with limited English proficiency. There is evidence that families from African American and Latinx and low-income families with CYSHCN are at higher risk for challenges related to health and well-being and may face different risks than other populations of CYSHCN.^{31,32} Currently, there is also a gap in our understanding of the factors and underlying mechanisms contributing to poor health outcomes for racially and ethnically diverse families and whether they face different risks. In addition, there is a significant knowledge deficit in the understanding of health and well-being of families with limited English proficiency who face unique challenges within the health care system.^{33,34} This is particularly notable with interventional studies, often due to challenges in providing interventions in multiple languages and measurement issues. Understanding how culture influences the health of families of CYSHCN could provide information that would be invaluable to improving the quality of family supports and the ability to provide culturally and linguistically competent care to all families. Barriers to

research include lack of trusting relationships (eg, based on past abuses of research subjects), lack of bi/multilingual researchers, measures that are validated only in English (or a limited selection of languages), limited diversity in the population of researchers, among others. Partnering with diverse families with lived experience and including them on research teams can help assure that the research will be relevant and helpful to all families.

HEALTH AND WELL-BEING OF ALL FAMILY MEMBERS

There is also a lack of literature focusing on the health and well-being of family members beyond parents, apart from some literature on siblings of CYSHCN. Research on siblings and other family members often relies on proxy reports, which may not fully represent the experiences of the intended respondent.³⁵ Grandparents raising CYSHCN and other kinship families are of particular concern as they often step into family caregiver roles unexpectedly and with minimal preparation, and reportedly may be reluctant to interfere with the parent-child relationship by taking over legal guardianship. In addition, there is a gap in the literature dedicated to families with multiple CYSHCN, foster families, and other underrepresented family structures.

RECOMMENDATIONS FOR FUTURE RESEARCH

Through the RAM process, key stakeholders identified one key priority recommendation specific to family health: "How can family adaptability be measured and improved?". Other family health priority topic categories related to family mental health and well-being were also identified as important areas for future research. Categories related to family health include family resilience, family mental health screening, support for family self-care and emotional needs, family mental health and addiction, and family stress. The RAM process also identified the importance of the influence of family health on child health. The identification of the importance of family mental health and resilience is clear and points to the need to create systems that work for and with families to support their identified needs as a means to support their mental health. Family mental health and resilience connects to child well-being and flourishing.¹⁸

Although not identified as a separate family-related issue during the RAM process, it is critical to focus on issues of equity and to engage families who are experiencing these inequities as equal partners in the work. Families of CYSHCN are particularly vulnerable to disparities in health care. Issues related to disability, race, ethnicity, racism, poverty, language, and health literacy, among others, drive unacceptable inequities in care and outcomes for CYSHCN. Consideration of these issues in CYSHCN research in the context of the whole family rather than the individual child will lead to more comprehensive understanding of the needs of children and families and potential strategies for improvement. Partnering with families from affected communities as authentic research partners to identify, for example, what constitutes an appropriate

Recommendations for future research topics related to families of CYSHCN

- Improve measurement of family health including adaptability, resiliency, and flourishing as outcomes of research.
- Conduct observational and interventional trials that seek to improve family mental health, flourishing, resiliency, and adaptability.
- Broaden the study of family characteristics including family health and wellbeing on utilization of healthcare and health outcomes of CYSHCN.

Figure. Recommendations for future research topics related to families of CYSHCN. CYSHCN indicates children and youth with special health care needs.

sample for an individual question and how to obtain unbiased samples that are representative of the population being studied is essential to effective research. In some situations, it may be important to study subpopulations or oversample groups that lack access to care and/or good health care outcomes.

The 3 primary areas of recommendation related to family health that were derived from the RAM process are described above (Figure). First, research should improve the measurement of family health including adaptability, resiliency, and flourishing as outcomes of research. This work should focus on outcomes that have been defined by and are important to families such as flourishing, resiliency, and adaptability along with other factors that promote family mental. Observational studies utilizing these outcome measures will determine factors that are associated with them and will identify moderating and mediating factors. Elucidation of these factors will enable family and professional research teams to develop and evaluate targeted interventions to promote family mental health and well-being.

To lay the foundations to study these complex domains, further measurement work is needed. Taking advantage of work that has been done in the social sciences including theoretical work will be useful in creating and/or identifying valid, reliable, psychometrically robust measures of outcomes. These studies might include testing the properties of outcomes measures for their sensitivity to change, their validity and reliability, their psychometric properties in populations of families of CYSHCN, in different subgroups of families, and/or in different languages. It might also include qualitative research to inform measure development and to assure that family preferences are built into measure development. This will inform the choice of standardized and validated outcome measures that may be used across observational and interventional studies, increasing the ability to synthesize the findings of multiple studies. For example, studies of medical home models, care coordination, parent coaching, mind body, and other interventions could utilize these common outcome measures to allow assessment across interventions. This work will need to be mindful of how culture and language is addressed in measurement development and use so that studies can be conducted in diverse populations.

The second recommended focus area for research on family health is the assessment of and testing interventions related to mental health including work related to flourishing, resiliency, and adaptability. Research focusing on interventions to improve caregiver well-being

should be developed or draw from other populations. For example, the use of mindfulness-based stress reduction, which has been useful in adult caregivers of dementia patients, has shown promise in caregivers of children with autism and future work may concern this application in other populations.^{36,37} This work could be extended to studies of broad groups of parents of CYSHCN. Similarly, although there is literature showing substantial gaps in respite care for families of CYSHCN, more research is needed to show the short- and long-term impacts of respite care on family mental health and evidence of successful methods to improve the availability of such programs. Other possible interventions include the medical home (and components thereof), care coordination, parent support groups, peer mentorship, the organization of care, care in the home, and policies that influence the receipt and delivery of care to children and youth.

As noted above, this work should include considerations of race, ethnicity, language, family structure, which family members are considered, among other elements that may impact interventions to influence outcomes. Understanding which families are most at risk, which interventions work and for which populations, and which interventions will contribute to reducing disparities will contribute to improved and equitable outcomes. Studies in this area might also compare different state or local policies related to family support and whether they improve outcomes and reduce inequality. Understanding how systems might provide personalized treatment and supports to meet the identified needs of families is also crucial.¹⁸

In addition to identifying the most useful interventions, more research is needed focusing on implementation science. Implementation science could inform the broad uptake and success of clinical interventions, social and community supports, and health and social policies that identify and influence family physical health, mental health, flourishing, resilience, and adaptability. One implementation framework, the RE-AIM framework of implementation science considers variables related to reach, adoption, implementation, maintenance, and evidence.³⁸ Using this or other frameworks could improve the uptake and delivery of successful interventions.

Third, further research is needed to consider how the health of CYSHCN is influenced by family health and well-being. The consideration of family health variables in studies of CYSHCN and their health at this time is often limited to parental marital status and socioeconomic status. Consideration in these studies of theoretically derived and hypothesized mechanisms of the influence

may identify a broader set of family characteristics to consider in future studies. For example, studies often include some variables that measure family structure, such as number of individuals in the household or marital status of a parent respondent. Different aspects of family structure might be relevant for any given study. Different considerations of what aspect of family structure are of interest and why might lead to different family structure variables being considered in analyses. In being more precise and thoughtful the analyses may reveal areas where systems changes could help families. To take a simple example, if there are no adults available to take a child to an appointment in the middle of the day then could clinics stay open later? Could health care services happen in the home or at school? Could visits be bundled so that they use the family's time more efficiently and require less time off from work?

CONCLUSIONS

Family health is an important outcome to consider in research focusing on CYSHCN. Research has demonstrated families of CYSHCN to be at risk for challenges related to their health and well-being; however, families are also resilient and can thrive with a supportive health care system. Gaps remain in the literature including a focus on understanding measurement of flourishing resilience and adaptability of families of CYSHCN; interventions supporting family physical and mental health; and understanding the impact of family health on CYSHCN outcomes. In addition, future research should focus on equitable understanding of diverse families of CYSHCN. This paper describes the recommendations of the CYSHCN research network RAM process for family health. The suggestions aim to improve the consideration of novel family factors as outcomes and as inputs when considering the health of CYSHCN and to do so in a way that will also increase equity.

ACKNOWLEDGMENTS

Financial statement: This program is supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) under [UA6MC31101](#) Children and Youth with Special Health Care Needs Research Network.

This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, and the US Government.

LPFCH funding: Support for this work was provided by the Lucile Packard Foundation for Children's Health's Program for Children with Special Health Care Needs. We invest in creating a more efficient system that ensures high-quality, coordinated, family-centered care to improve health outcomes for children and enhance quality of life for families. The views presented here are those of the authors and do not reflect those of the Foundation or its staff.

This paper is part of a supplement supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) and the Lucile Packard Foundation for Children's Health's Program for Children with Special Health Care Needs.

REFERENCES

1. Coller RJ, Berry JG, Kuo DZ, et al. Health system research priorities for children and youth with special health care needs. *Pediatrics*. 2020;145: e20190673. <https://doi.org/10.1542/peds.2019-0673>.
2. Pilapil M, Coletti DJ, Rabey C, et al. Caring for the caregiver: supporting families of youth with special health care needs. *Curr Probl Pediatr Adolesc Health Care*. 2017;47:190–199.
3. Caicedo C. Health and functioning of families of children with special health care needs cared for in home care, long-term care, and medical day care settings. *J Dev Behav Pediatr*. 2015;36:352–361.
4. Keilty K, Cohen E, Spalding K, et al. Sleep disturbance in family caregivers of children who depend on medical technology. *Arch Dis Child*. 2018;103:137–142.
5. Gallagher S, Phillips AC, Drayson MT, et al. Parental caregivers of children with developmental disabilities mount a poor antibody response to pneumococcal vaccination. *Brain Behav Immun*. 2009;23:338–346.
6. Lovell B, Moss M, Wetherell M. The psychosocial, endocrine and immune consequences of caring for a child with autism or ADHD. *Psychoneuroendocrinology*. 2012;37:534–542.
7. Lutenbacher M, Karp S, Ajero G, et al. Crossing community sectors: challenges faced by families of children with special health care needs. *J Fam Nurs*. 2005;11:162–182.
8. Goudie A, Havercamp S, Jamieson B, et al. Assessing functional impairment in siblings living with children with disability. *Pediatrics*. 2013;132:e476–e483.
9. Feragen KB, Stock NM, Myhre A, et al. Medical stress reactions and personal growth in parents of children with a rare craniofacial condition. *Cleft Palate Craniofac J*. 2020;57:228–237.
10. Cochrane JJ, Goering PN, Rogers JM. The mental health of informal caregivers in Ontario: an epidemiological survey. *Am J Public Health*. 1997;87:2002–2007.
11. Collins A, Burchell J, Remedios C, et al. Describing the psychosocial profile and unmet support needs of parents caring for a child with a life-limiting condition: a cross-sectional study of caregiver-reported outcomes. *Palliat Med*. 2020;34:358–366.
12. Sharpe D, Rossiter L. Siblings of children with a chronic illness: a meta-analysis. *J Pediatr Psychol*. 2002;27:699–710.
13. Chung PJ, Garfield CF, Elliott MN, et al. Need for and use of family leave among parents of children with special health care needs. *Pediatrics*. 2007;119:e1047–e1055.
14. Kuhlthau K, Hill KS, Yucel R, et al. Financial burden for families of children with special health care needs. *Matern Child Health J*. 2005;9:207–218.
15. Rose-Jacobs R, Ettinger de Cuba S, Bovell-Ammon A, et al. Housing instability among families with young children with special health care needs. *Pediatrics*. 2019;144: e20181704. <https://doi.org/10.1542/peds.2018-1704>.
16. Rose-Jacobs R, Fiore JG, Ettinger de Cuba S, et al. Children with special health care needs, supplemental security income, and food insecurity. *J Dev Behav Pediatr*. 2016;37:140–147.
17. Patterson JM. Family resilience to the challenge of a child's disability. *Pediatr Ann*. 1991;20:491–499.
18. Bethell CD, Gombojav N, Whitaker RC. Family resilience and connection promote flourishing among US children, even amid adversity. *Health Aff (Millwood)*. 2019;38:729–737.
19. Churchill SS, Villareale NL, Monaghan TA, et al. Parents of children with special health care needs who have better coping skills have fewer depressive symptoms. *Matern Child Health J*. 2010;14:47–57.
20. Park ER, Perez GK, Millstein RA, et al. A virtual resiliency intervention promoting resiliency for parents of children with learning and attentional disabilities: a randomized pilot trial. *Matern Child Health J*. 2020;24:39–53.
21. Kuo DZ, Bird TM, Tilford JM. Associations of family-centered care with health care outcomes for children with special health care needs. *Matern Child Health J*. 2011;15:794–805.
22. Kieckhefer GM, Trahms CM, Churchill SS, et al. A randomized clinical trial of the building on family strengths program: an education program for parents of children with chronic health conditions. *Matern Child Health J*. 2014;18:563–574.

23. Kutash K, Duchnowski AJ, Green AL, et al. Supporting parents who have youth with emotional disturbances through a parent-to-parent support program: a proof of concept study using random assignment. *Adm Policy Ment Health*. 2011;38:412–427.
24. Compas BE, Jaser SS, Dunn MJ, et al. Coping with chronic illness in childhood and adolescence. *Annu Rev Clin Psychol*. 2012;8:455–480.
25. Babic R, Babic M, Rastovic P, et al. Resilience in health and illness. *Psychiatr Danub*. 2020;32(suppl 2):226–232.
26. Gilson KM, Davis E, Johnson S, et al. Mental health care needs and preferences for mothers of children with a disability. *Child Care Health Dev*. 2018;44:384–391.
27. Schellekens MPJ, van den Hurk DGM, Prins JB, et al. Mindfulness-based stress reduction added to care as usual for lung cancer patients and/or their partners: a multicentre randomized controlled trial. *Psychooncology*. 2017;26:2118–2126.
28. Whitebird RR, Kreitzer M, Crain AL, et al. Mindfulness-based stress reduction for family caregivers: a randomized controlled trial. *Gerontologist*. 2013;53:676–686.
29. Donley T, King DM, Nyathi N, et al. Socioeconomic status, family functioning and delayed care among children with special needs. *Soc Work Public Health*. 2018;33:366–381.
30. Lindly OJ, Chavez AE, Zuckerman KE. Unmet health services needs among US children with developmental disabilities: associations with family impact and child functioning. *J Dev Behav Pediatr*. 2016;37:712–723.
31. Mooney-Doyle K, Lindley LC. Family and child characteristics associated with caregiver challenges for medically complex children. *Fam Community Health*. 2020;43:74–81.
32. McManus BM, Carle A, Acevedo-Garcia D, et al. Modeling the social determinants of caregiver burden among families of children with developmental disabilities. *Am J Intellect Dev Disabil*. 2011;116:246–260.
33. Eneriz-Wiemer M, Sanders LM, Barr DA, et al. Parental limited English proficiency and health outcomes for children with special health care needs: a systematic review. *Acad Pediatr*. 2014;14:128–136.
34. Yu SM, Nyman RM, Kogan MD, et al. Parent's language of interview and access to care for children with special health care needs. *Ambul Pediatr*. 2004;4:181–187.
35. Dinleyici M, Carman KB, Ozdemir C, et al. Quality-of-life evaluation of healthy siblings of children with chronic illness. *Balkan Med J*. 2019;37:34–42.
36. Weitlauf AS, Broderick N, Stainbrook JA, et al. Mindfulness-based stress reduction for parents implementing early intervention for autism: an RCT. *Pediatrics*. 2020;145(suppl 1):S81–S92.
37. Kuhlthau KA, Luberto CM, Traeger L, et al. A virtual resiliency intervention for parents of children with autism: a randomized pilot trial. *J Autism Dev Disord*. 2020;50:2513–2526.
38. Ross C, Brownson GAC, Proctor EK. *Dissemination and Implementation Research in Health: Translating Science Into Practice*. New York: Oxford University Press; 2012.