



Psychosocial Factors in Children and Youth With Special Health Care Needs and Their Families

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Children and youth with special health care needs (CYSHCN) and their families may experience a variety of internal (ie, emotional and behavioral) and external (ie, interpersonal, financial, housing, and educational) psychosocial factors that can influence their health and wellness. Many CYSHCN and their families are resilient and thrive. Medical home teams can partner with CYSHCN and their families to screen for, evaluate, and promote psychosocial health to increase protective factors and ameliorate risk factors. Medical home teams can promote protective psychosocial factors as part of coordinated, comprehensive chronic care for CYSHCN and their families. A team-based care approach may entail collaboration across the care spectrum, including youth, families, behavioral health providers, specialists, child care providers, schools, social services, and other community agencies. The purpose of this clinical report is to raise awareness of the impact of psychosocial factors on the health and wellness of CYSHCN and their families. This clinical report provides guidance for pediatric providers to facilitate and coordinate care that can have a positive influence on the overall health, wellness, and quality of life of CYSHCN and their families.

abstract

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DOI: <https://doi.org/10.1542/peds.2018-3171>

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INTRODUCTION

Children and youth with special health care needs (CYSHCN) are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required for children generally.”¹ This definition has been used to guide the development of family-centered, coordinated systems of care for children with special needs and families who are served by many public and private health systems, most notably by state Title V block programs administered by the federal Maternal and Child Health Bureau. This report highlights

To cite: Mattson G, Kuo DZ, AAP COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Psychosocial Factors in Children and Youth With Special Health Care Needs and Their Families. *Pediatrics*. 2019;143(1):e20183171

psychosocial internal (emotional or behavioral) and external (interpersonal, housing, and financial) risk and protective factors that impact growth and development, health and wellness, and quality of life for CYSHCN and their families.² The report offers guidance for pediatric providers to address psychosocial risk and protective factors as part of comprehensive, coordinated care within the medical home. Such care should be delivered in partnership with families, mental and behavioral health providers, child care settings, schools, social services, and other professionals and community agencies across the care spectrum. This report complements other pediatric literature in which screening and surveillance, discussion, and the management of threats to social, behavioral, emotional, and mental health in all children are addressed.^{3–7}

CHANGING EPIDEMIOLOGY OF CYSHCN

According to the 2016 National Survey of Children's Health (NSCH), 19.4% of children and youth have special health care needs.⁸ This is an increase from 15.1% found in the 2009–2010 National Survey of Children with Special Health Care Needs.⁹ Racial and ethnic disparities are seen in prevalence, resource use, and survival rates between children who have more medically complex and less complex physical, mental health, and developmental conditions.^{10–16} Studies reveal that families caring for CYSHCN experience more significant financial and caregiving demands than families of children without special health care needs.^{8,9,17} Few CYSHCN (3.8%) were reported to be uninsured on the 2016 NSCH, but 29.6% of parents of CYSHCN reported inadequate insurance coverage, compared with 23.6% of parents of children without special health care needs.⁸

National surveys have shown a significant increase in the overall prevalence and severity of specific chronic conditions, including asthma, diabetes mellitus, and obesity.^{11,18–22} The 2015 data from the National Health Interview Survey of the Centers for Disease Control and Prevention show a current overall asthma prevalence of 8.4% among children younger than 18 years. However, there is racial disparity, as non-Hispanic African American children have a 13.4% prevalence of asthma.¹⁸ There have been disproportionate increases in the prevalence of obesity and severe obesity among Hispanic, non-Hispanic African American, and American Indian and/or Alaskan native children.^{20,21,23} There is also a disproportionate increase in type 2 diabetes mellitus, which is believed to be related to increasing rates of obesity,^{24,25} especially in African American and American Indian and/or Alaskan native children.^{22–25}

The prevalence of children with medical complexity (CMC), who represent the most resource-intensive subset of CYSHCN, is also increasing. CMC typically include children with congenital, genetic, or acquired multisystem conditions who have multiple subspecialty needs as well as children with a dependence on technology for daily needs.^{17,26,27} The increase in CMC is possibly related to advances in neonatal care and additional life-saving technologies.^{28–30} Despite being a small subset of CYSHCN, CMC account for an increasing proportion of pediatric inpatient admissions, with hospitalization rates that doubled between 1991 and 2005.^{31,32}

The overall prevalence of children with a behavioral, mental health, learning, or developmental disability as their primary chronic health condition is increasing in the United States.^{6,7} Parent surveys indicate that the prevalence of attention-deficit/hyperactivity disorder (ADHD)

(currently 8.9% of children),⁸ autism spectrum disorders (2.5% of children),⁸ and bipolar disorders (2.2% among youth)³³ have increased over the last 2 decades.^{6,7,34} ADHD has been found to be highest in the non-Hispanic multiracial group and lowest among Hispanic children. Behavioral or conduct problems are highest among non-Hispanic African American children, and autism spectrum disorders tend to be higher among non-Hispanic white children.⁷ Speech disorders, ADHD, and learning disabilities are among the leading causes of limitations in play or school for children attributable to a chronic condition, and there has been a receding in importance between 1979 and 2009 in the numbers of respiratory, eye, ear, and orthopedic conditions that cause limitations for children.³⁵

According to the 2016 NSCH, 42.4% of CYSHCN were reported to have an emotional, developmental, or behavioral issue.⁸ Behavioral health can strongly influence health and wellness outcomes for all children and especially for CYSHCN.³⁶ Reviews of the literature have shown that children with chronic physical health and developmental conditions are at an increased risk for having co-occurring mental health or behavioral problems or conditions.^{37,38} Internalizing problems and conditions, ranging from low self-esteem and worry to depression and anxiety, can occur in CYSHCN. CYSHCN also can experience externalizing problems and conditions, ranging from attention problems and defiant and aggressive behaviors to ADHD, conduct disorder, and oppositional defiant disorder.^{38–40}

Associations of chronic illnesses with psychological and behavioral conditions, such as anxiety and depression, are well described. Such associations may be explained by biological causes, such as inflammatory processes with asthma

or diabetes, and psychological causes, such as the stress of living with an adverse and potentially life-threatening condition.^{36,41,42} Studies in adults reveal that comorbid mental and physical illnesses can result in more health care service needs, functional impairment, and higher medical costs compared with similar physical illnesses without the co-occurring mental health condition.⁴³ Fewer studies have been conducted in children, but 1 study suggests that mental health encounters may encompass a large proportion of outpatient use for some CMC.⁴⁴ A focus on psychosocial factors and wellness would appear to be an important addition to the overall chronic care model for CYSHCN.³⁶

IMPACT OF PSYCHOSOCIAL FACTORS ON OVERALL HEALTH AND WELLNESS FOR CYSHCN AND THEIR FAMILIES

The biological, physical, emotional, and social environments strongly affect the capacity for children to be healthy over their life course trajectory.⁴⁵ External psychosocial factors include social determinants of health (SDH), which are defined by the Kaiser Family Foundation and World Health Organization as the “conditions in which people are born, grow, live, work and age.”⁴⁶ The Centers for Disease Control and Prevention Essentials for Childhood initiative emphasizes that “[s]afe, stable, nurturing relationships and environments are essential to prevent child maltreatment...and to assure that children reach their full potential” over their lives.⁴⁷ SDH, such as housing stability and food security, have a positive influence on the health of all children and are recommended to be addressed during well-child visits.^{5,46,48} Studies suggest that poor housing and neighborhood quality are associated with a greater risk for some CYSHCN experiencing a poorer quality of life.^{49,50} Food insecurity may also impact CYSHCN specifically if they

have increased or specialized nutritional needs or dietary restrictions.⁵¹

CYSHCN have higher rates of exposure to adverse childhood experiences (ACEs) or toxic stress (eg, abuse and domestic violence).⁸ According to the 2016 NSCH, 37% of CYSHCN had 2 or more ACEs, compared with 18% of children without special health care needs.⁹ These ACEs are often internalized, but the negative effects may be mitigated over time by protective factors.^{52–54} In addition, children with 2 or more ACEs are significantly more likely to be considered CYSHCN compared with children with no exposure to ACEs.⁵³ The presence of 2 or more ACEs can be linked to exacerbations of their chronic conditions, an increased risk of developing secondary conditions, poor school engagement, and even an increased risk of repeating a grade in school.^{52,53} Exposure to 2 or more ACEs may be associated with smoking, using drugs, participating in earlier sexual activity, and performing violent or antisocial acts.^{53,54} If CYSHCN engage in these risky behaviors, there may be an increased risk for additional short- and long-term physical and mental health problems and difficulties with following treatment recommendations as well as an increased risk for poorer health care outcomes.^{50,55,56} However, studies show that CYSHCN who learn and show resilience may be able to reduce the negative effects of some ACEs. This mitigation of risk occurs especially when supports are provided for key transition points, such as starting child care, school, and work.^{52,53}

Children with intellectual or developmental disabilities may be at an increased risk for physical, emotional, and sexual abuse and neglect. The reasons may include inadequate social skills, limited capacity to find help or report abuse,

lack of strategies to defend against abuse, or increased exposure to multiple caregivers and settings.^{57,58} Additional challenges can occur if parents of children with disabilities lack respite, coping skills, or adequate social and community support. These stressors can put some children at risk for failing to receive needed medications or adequate medical care and can lead to abuse or neglect.⁵⁹

Additional family stressors not considered ACEs can still negatively affect the health of some CYSHCN. These stressors include, but are not limited to, caregiver burden, poor coping skills, inadequate sleep, limited interactions with extended family and friends, reductions or loss of parental employment, and financial problems.^{60–65} Family conflict, in particular, can be associated with a greater number of hospitalizations, as seen in 1 study for children with asthma.⁴¹ Financial problems may result from multiple and costly medications, equipment, therapies or specialty appointments, and loss of income from taking time off work to care for CYSHCN.^{17,66} Limited English proficiency in parents and lack of insurance are 2 stressors that may disproportionately affect the health and well-being of some immigrant families of CYSHCN.⁶⁷ Parenting stress may increase if negative perceptions of their child’s illness occur, potentially leading to additional mental and physical health problems in the parents of some CYSHCN.⁶⁸ Siblings of some CYSHCN with developmental disabilities and cancer may be at risk for emotional and behavioral problems, difficulties with interpersonal relationships and functioning at school, and psychiatric conditions.^{69,70} The effects on caregiver and family stress can be even greater in families with children who have higher medical complexity.^{17,71}

Child care and school settings may struggle to accommodate the needs of CYSHCN, leading to increased stress, poor socialization, and poor school performance.^{49,50,72–75} Some CYSHCN may lose motivation to do well in school, resulting in lower academic achievement and increased school absences.⁷⁵ Some CYSHCN may experience bullying, stereotyping, prejudice, or stigmatization from peers or others in their schools or communities. This negative experiences may lead to difficulties in school, including school avoidance.^{50,76,77} Children with intellectual and developmental disabilities, seizure disorders, and other conditions affecting the central nervous system are at particular risk for school problems because of impairments in brain growth and development^{78–80} with resultant effects on executive functioning skills.^{38,78,80,81} Problems with attention, memory, language, and understanding social processes place some CYSHCN at an increased risk for academic failure, poor interpersonal skills, and low self-esteem.^{38,78,80–82} Negative school experiences may also further exacerbate problems with adherence to medications, therapies, or other health recommendations at school.⁸³

The cumulative effects of living with and managing a chronic condition may evolve further over the life span of a child.^{84,85} Certain chronic physical and mental health conditions and treatments, particularly those affecting the central nervous system, may affect neurologic and cognitive function, social development, emotional regulation and awareness, and expressive and receptive communication. These effects may not be readily apparent to families, caregivers, teachers, and health care providers.^{84–86} Developmental, social, and behavioral problems may be observed when age-appropriate and interpersonal competencies, abilities, and skills are not achieved.^{38,78,87–90}

Escalation in levels of needed medical care can increase the development of additional mental or behavioral health problems or social concerns in children. These developments can present additional challenges in the home and in child care and school settings.^{38,78,87,88,91,92}

A negative illness perception, low self-esteem, and a belief of a lack of control can increase the risk of a co-occurring mental health concern or diagnosis in some children.^{93,94} Stress from unrecognized and/or untreated mental health concerns can result in increased cortisol levels, which can negatively affect physiology and metabolism and exacerbate chronic conditions, such as asthma or diabetes.⁸⁷ Unrecognized and untreated chronic complications among CYSHCN can increase the risk of developing internalizing or externalizing behavioral problems or conditions.^{95,96} For example, chronic nocturnal symptoms with uncontrolled asthma or undiagnosed sleep apnea with Down syndrome can negatively affect behavioral health and quality of life.⁹⁷ Co-occurring chronic physical and mental health conditions are associated with an attempted suicide risk in excess of that predicted by the chronic mental health condition alone.⁹⁸ A focus on behavioral health and wellness as part of chronic care may help improve health outcomes for some CYSHCN and their families.³⁶

SUPPORTING PSYCHOSOCIAL PROTECTIVE FACTORS FOR CYSHCN AND THEIR FAMILIES

Psychosocial protective factors can be supported at the individual, interpersonal, and community levels. Supportive and stable relationships, processes, and policies that promote resilience benefit children and can buffer against ACEs.^{99–103} Developmentally appropriate and supported cognitive, language, and communication skills and abilities

may be associated with calmer temperament and higher levels of self-esteem, which can aid in coping with a chronic illness.^{40,104–106} Skills for social competence have been taught by caregivers to encourage cooperation, self-control, assertion, and self-responsibility in children with mobility disorders.⁹⁹ Protective factors in some children with malignancies include comparing themselves with other children with malignancies instead of healthy peers, using positive reappraisal, spiritual or religious coping, and future-oriented thinking.^{107–109}

Studies now show the importance of supporting families and communities that help CYSHCN to have positive relationships and interactions.¹⁰³ Healthy and well-functioning families may offer coping assistance for some CYSHCN.^{108,110} Cohesive and connected families with stable family structures seem to be most functional.^{60,110} Studies of children with autism, asthma, and diabetes suggest that instilling positive parenting beliefs helps engage parents in appropriate care.^{111–114} Education of community members about a child or youth's medical condition may increase coping and resilience in some families.¹¹⁰ A father's involvement in the care of a child with a chronic disease has been associated with higher treatment adherence, better psychological adjustment, and improved health for the child.¹¹⁵ Higher social support for caregivers of CYSHCN has been associated with decreased psychological distress in the child and decreased risks for stress, loneliness, depression, and anxiety in caregivers.¹¹⁶

Schools can be a source of strength when there are positive parent-school partnerships and a supportive, coordinated early intervention system.^{73–75} Health care providers and schools can collaborate with families on monitoring changes in health status, developing the

treatment plan, and ensuring appropriate school staffing.^{117,118} Schools, in partnership with families and health care providers, can play a significant role in supporting self-management of care for CYSHCN and other elements of health care transition.¹¹⁹ Families, youth, providers, and school and child care staff can develop and modify an Individualized Family Service Plan, Individualized Education Program, 504 plan, or individualized health plan on the basis of medical and psychosocial needs and supports. These supports may include self-management of care and transition to adult health care systems.^{117,119–122}

Fully supporting protective factors involves the development of community-based systems of care for CYSHCN that address psychosocial aspects of care.^{123,124} A system of care represents a coordinated network of community-based services and supports, including the family, the medical home, child care providers, and schools. The core values include building on the strengths and needs of the youth and family. This approach has resulted in improvements in multiple domains of individual and family functioning, including the reduction of family stress and strain and increased behavioral and emotional strengths in children.¹²⁵

ADDRESSING PSYCHOSOCIAL FACTORS IN THE MEDICAL HOME

The pediatric medical home is an ideal setting to address psychosocial factors that impact wellness and resilience for CYSHCN and their families. The medical home can conduct ongoing surveillance and screening for psychosocial factors and promote care coordination of needed services and supports.^{126,127} Longitudinal, relationship-centered care may facilitate discussions about psychosocial factors, address symptoms, and increase adherence

to recommendations.^{127–130} Pediatric primary care and specialty providers can promote team-based care with partners from multiple disciplines by coordinating psychosocial screening, care planning, and interventions. Additional key partners may include care managers, family navigators, social workers, psychologists, professional interpreters, and public health and social service agencies.¹³¹ Access to comprehensive care for CYSHCN through a medical home is associated with improvements in health status, access to care, and family satisfaction. Use of a medical home approach is also associated with fewer missed school days for children, issues with child care, missed days of work, and out-of-pocket costs for families.^{8,9,126,132–134}

In the 2017 *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents, Fourth Edition*, the American Academy of Pediatrics (AAP) emphasizes a strength-based approach to comprehensive care and wellness for all children. The need to particularly focus on health and wellness for CYSHCN is also recognized.⁵ AAP *Bright Futures* recommendations for preventive pediatric health care include developmental surveillance, general developmental screening, and screening for autism at specific ages during well-child visits.^{5,135–136} Recommended surveillance and screenings are important even in the presence of an existing chronic physical or mental health condition, a developmental delay, or a disability, when appropriate.

The AAP *Bright Futures* recommendations include a psychosocial and behavioral assessment at every well-child visit that is “family centered and may include an assessment of child social emotional health, caregiver depression, and social determinants.”^{5,135} *Bright Futures* and the US Preventive Services Task Force recommend screening for

both postpartum depression and depression in adolescents at specified well-child visits.^{5,137–139} Surveillance or screening for parental socioemotional well-being and SDH outside of the postpartum period may identify additional psychosocial risk factors for CYSHCN.^{19,50,53,54,60,61,63–65} The AAP policy statement “Poverty and Child Health in the United States”⁴⁸ and an additional article about redesigning health care to address poverty¹⁴⁰ provide recommendations and resources for screening tools for SDH (eg, Safe Environment for Every Kid [SEEK]).

A variety of resources can help pediatric medical home providers address psychosocial risk factors using a team-based approach. These include the AAP Mental Health Initiatives Web site (<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Pages/Primary-Care-Tools.aspx>), a tool kit called Mental Health Screening and Assessment Tools for Primary Care,¹⁴¹ articles and resources from the AAP Task Force on Mental Health published in a June 2010 supplement to *Pediatrics*,¹⁴² and a recent clinical report (“Promoting Optimal Development: Screening for Behavioral and Emotional Problems”⁴) that provides resources about specific behavioral and emotional tools and processes. The AAP Screening, Technical Assistance, and Resource Center provides a variety of resources about screening, discussion, management, and referral in primary care around child development, maternal depression, and SDH for young children (<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Screening/Pages/default.aspx>). These developmental, autism, and social-emotional screening tools were validated in the general population and normalized for typically developing children.^{4,5,139,141,143,144} Validated

quality-of-life screening questions have been used across several conditions, although more in research settings than in primary care.¹⁴⁵ Standardized care approaches and tools can be used to facilitate self-management that addresses psychosocial needs, adherence to treatment plans, and leverage of supportive community resources.^{146,147}

Pediatric providers are encouraged to develop mental health competencies for direct patient care and for coordination with community resources.³ Pediatric providers can use evidence-based techniques (eg, motivational interviewing) to address mental health concerns and social determinants identified with screening in the medical home setting. Such approaches may be used by providers while waiting for further evaluation of the child and even while a child is receiving treatment by a mental health provider.^{3,130} Interventions may include counseling about family-focused physical activity guidelines, good nutrition, and improved sleep routines.^{36,131} Common elements among psychosocial interventions include the use of motivational interviewing strategies to communicate hope, empathy, and loyalty; use of plain language; asking permission to ask questions or share information; and partnering with families.¹³⁰ Such elements have been found to be effective in building alliances, increasing disclosure, and facilitating discussions about psychosocial strengths and concerns.^{129,130} Pediatric providers on the care team may not serve as the primary provider to deliver mental health counseling and interventions, but they can support integrated interdisciplinary efforts and partnerships.³⁶ A team-based approach may include the use of designated staff for wellness promotion, collocation of services (eg, social workers

and psychologists), or referrals to community services for mental health assessment, counseling, and interventions.¹³¹

Behavioral health integration has been described as a useful “approach and model of delivering care that comprehensively addresses the primary care, behavioral health, specialty care, and social support needs of children and youth with behavioral health issues in a manner that is continuous and family-centered.”¹⁴⁸ Behavioral health integration can aid the medical home as needs occur from infancy through adolescence and into young adulthood.¹⁴⁹ Practices with collocated behavioral health providers or real-time access to short-term mental health support have seen improved timely evaluations of child and family functioning, increased referrals for more specialized evaluations, and improved access to direct behavioral health services for CYSHCN.^{3,150} Mindfulness and relaxation training may also be effective with stress and can be taught to parents and children.¹⁵¹ However, not all practices have collocated or integrated behavioral health providers; therefore, pediatric providers are encouraged, as mentioned earlier, to develop some mental health competencies for use in primary care to enhance their delivery of direct patient care and coordination with community resources.³ Formal care coordinators, as part of the medical home team, can assist with identifying and strengthening protective relationships to help support and monitor strategies and interventions with child care providers, schools, home health agencies, behavioral health providers, social service workers, and a variety of other professionals.¹⁵² Care coordinators can be employed by the practice or another entity and can help facilitate management and referral

and follow-up related to community resources.^{3,140,152}

These community relationships can help increase awareness, communication, and transparency of the care directed by the medical home.¹⁵² The medical home, in partnership with care coordinators and community partners, may promote planned transition from pediatric to adult health care that addresses psychosocial risk and protective factors. Planned transition includes structured assessments and planning (beginning in early adolescence) addressing SDH as well as guardianship and other legal issues. The goal is to minimize breaks in continuous care and lessen parental concern, particularly for chronic conditions accompanied by cognitive impairment.¹¹⁹

Implementation of the medical home model entails a quality improvement approach and practice transformation activities. Such activities may include a patient registry, care tracking, team-based care, and special care protocols. Strategies could include a previsit process that may include routine psychosocial screening, scheduling additional time during appointments, and identifying a team member and/or care coordinator. Additional efforts include electronic health record integration and workflow changes to incorporate screening, discussion, referrals, and follow-up as part of a comprehensive, integrated plan of care. Such a plan of care includes patient- and family-identified psychosocial goals and priorities.^{48,124,153}

Individual provider and practice challenges to the medical home include time, training, and lack of knowledge about available resources.^{4,154} Community and system barriers include inadequate payments, a shortage of pediatric psychiatrists and developmental-behavioral pediatricians,¹⁵⁵ limited community mental health resources,

and limited services and abilities in communities to address SDH (eg, housing).^{48,149} Flexible population-based payment models and the use of payment incentives could help to encourage increased management of psychosocial health and well-being as part of care for chronic conditions and could help to increase the use of more screening tools.^{48,153}

ADDITIONAL STRATEGIES TO SUPPORT SYSTEMS ADDRESSING PSYCHOSOCIAL FACTORS

Pediatricians represent only 1 stakeholder interested in the comprehensive system of care for CYSHCN and their families. Title V Maternal and Child Health programs, health plans, insurers, state Medicaid and Children's Health Insurance Program agencies, children's hospitals, health services researchers, families, and consumers developed national standards for a system of care for CYSHCN in 2014 and then updated these standards in 2017.¹²⁴

Recommendations for pediatric medical home teams include developing processes and protocols in collaboration with other community agencies (eg, Part C early intervention and home health) and professionals. These agencies may also perform psychosocial screenings and refer CYSHCN for further assessment of concerns. Collaboration could allow the medical home team to reduce duplication of efforts and ensure referred services regardless of who conducted the screening. Service linkage, timely communication, and appropriate data sharing can be used to promote an integrated plan of care that includes psychosocial goals and priorities from CYSHCN and their families.¹²⁴ The resource titled *Managing Chronic Health Needs in Child Care and Schools*⁷² and the AAP policy statement on the role of school nurses and the medical home¹¹⁷ offer

collaborative strategies to support social-emotional health, which influences health, school attendance, and academic performance.^{117,118}

Pediatric medical home providers and parents can learn about and be linked to several home- and community-based services and supports to help assess and address psychosocial needs for CYSHCN and their families. Respite care, palliative care, and hospice care and home-based services are examples of these services.¹²⁴ Parents may be supported through home visiting and parenting support programs regardless of whether they are specific for CYSHCN.^{156–158} One parenting program, called the Positive Parenting Program or Triple P, offers a series of parenting modules called Stepping Stones, which was developed specifically for use with parents of children with developmental disabilities. Stepping Stones modules address self-efficacy, self-sufficiency, self-management, personal agency, and problem solving with parents of children with developmental disabilities. However, not all states offer Triple P Stepping Stones modules, and some states that do offer it have limited access to these modules.^{159,160} Parent-to-parent support groups may help some families of CYSHCN share a social identity, experience personal growth, and learn coping strategies.¹⁶¹

Several programs serve as clearinghouses about services and supports for families. One example is the early childhood coordinated referral and system building programs called Help Me Grow (www.helpmegrwnational.org/). Help Me Grow is now available in 26 states to help connect providers and families to developmental screening and services.¹⁴⁰ The Community Services Locator (<https://www.nccemch.org/knowledge/community.php>) is another clearinghouse of information that provides Web sites and phone numbers that can be used

to assist with accessing national, state, and local resources for child care, early childhood education, special education services, family support, financial support, health and wellness, and parenting programs.¹⁴⁰ A third example is the United Way 211 line (<http://www.211.org/pages/about>), which is a telephone and Internet-based resource that is available 24 hours a day, 7 days a week, throughout most of the United States.¹⁴⁰ The 211 line can provide information about a wide variety of resources in multiple languages about housing, food pantries, and utilities in addition to child care, early education, and many other services to address SDH.¹⁴⁰

RECOMMENDATIONS

Health and wellness for CYSHCN are particularly sensitive to psychosocial risk and protective factors. Pediatric providers, particularly from the primary care-based medical home, are in the position to screen for, manage, and coordinate longitudinal care in which psychosocial factors of health among CYSHCN and their families are addressed. The following suggestions are offered to pediatricians involved in caring for CYSHCN:

1. Follow *Bright Futures* recommendations and guidance for CYSHCN and their families. Recommendations include the promotion of health and wellness as well as timely assessments of child social-emotional health, parental and/or caregiver depression, and SDH.
2. Use practice transformation strategies, such as quality improvement, patient registries, and previsit planning, to promote psychosocial screening and assessment, referrals, and follow-up among CYSHCN and their families. A good resource is the AAP Practice Transformation site (<https://www.aap.org/en-us/>)

professional-resources/practice-Transformation/Pages/practice-transformation.aspx).

3. Use team-based care strategies, care protocols, and dedicated care coordinators (if available) to recognize psychosocial protective factors and ameliorate risk factors. This strategy may involve collocation, consultation, comanagement, and/or integration with behavioral health specialists as part of medical home and specialty care teams.
4. Consider strategies for working with child care and school staff to monitor progress, reduce absences, and improve learning experiences and academic performance for CYSHCN.
5. Advocate for flexible payment redesign with Medicaid and other insurers. Payment redesign may better support wellness and chronic care management for CYSHCN and their families. Flexible payment redesign may include payments for mental health treatment, care coordination, and collocation or comanagement with behavioral health and other specialists or disciplines.
6. Promote evidence-based interventions and strategies in the medical home and subspecialty settings to support psychosocial development of CYSHCN, parenting competencies, and family resilience.
7. Advocate for research on adaptations of existing psychosocial screening tools and interventions for CYSHCN.

8. Advocate for community-based resources and strategies to address SDH and the reduction of disparities for CYSHCN and their families.
9. Pediatric providers and state AAP chapters can partner with Title V Maternal and Child Health CYSHCN programs in supporting implementation of the Association of Maternal and Child Health Program's Standards for Systems of Care for CYSHCN. These standards include increasing access for CYSHCN to quality medical homes, ease of use of community services, and transitioning across the life span.

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ABBREVIATIONS

AAP: American Academy of Pediatrics
ACE: adverse childhood experience
ADHD: attention-deficit/hyperactivity disorder
CMC: children with medical complexity
CYSHCN: children and youth with special health care needs
NSCH: National Survey of Children's Health
SDH: social determinants of health

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Pediatrics 2019;143;

DOI: 10.1542/peds.2018-3171 originally published online December 17, 2018;

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