

Position Statement on Children and Youth With Special Health Care Needs: Key Issues on Care Coordination, Transitions, and Leadership

National Association of Pediatric Nurse Practitioners *Children and Youth
with Special Health Care Needs Special Interest Group,
Elizabeth A. Doyle, DNP, APRN, PPCNP-BC, CDE,
David Geyer, MSN, RN, CPNP-PC,
Traci R. Gonzales, MSN, APRN, CPNP-PC, AE-C,
Tomika Harris, DNP, APRN, CPNP-PC, Siem Ia, RN, MS, CPNP-PC,
Talena Kerr, MSN, APRN, CPNP, & Jane Tobias, DNP, CRNP, CPNP-PC

Conflicts of interest: None to report.

Adopted by the National Association of Pediatric Nurse
Practitioners' Executive Board on November 6, 2020.

This document replaces the 2015 "Position Statement on
Pediatric Health Care/Medical Home: Key Issues on Care
Coordination, Transitions, and Leadership." All regular position
statements from the National Association of Pediatric Nurse
Practitioners automatically expire 5 years after publication unless
reaffirmed, revised, or retired at or before that time.

Copyright © 2021 by the National Association of Pediatric Nurse
Practitioners. Published by Elsevier Inc. All rights reserved.

Published by Elsevier Inc. All rights reserved.

Correspondence: National Association of Pediatric Nurse
Practitioners, 5 Hanover Square, Suite 1401, New York, NY
10004.

J Pediatr Health Care. (2021) 35, 317-319

0891-5245/\$36.00

<https://doi.org/10.1016/j.pedhc.2021.02.002>

Children and youth with special health care needs (CYSHCN) are defined as children who have or are at increased risk for having chronic physical, developmental, behavioral, or emotional conditions. A small and growing subset of CYSHCN often referred to as children with medical complexity, have complex chronic conditions that involve several organ systems and require multiple subspecialists, technological supports, and community services (Gordon et al., 2007). CYSHCN use higher levels of health care and other related services than their peers (McPherson et al., 1998). CYSHCN accounts for nearly 20% of all children aged less than 18 years in the United States (Health Resources and Services Administration, Maternal and Child Health Bureau, 2020). These children and their families often interact with multiple health care and medical service providers throughout their health care journey. To reach optimal outcomes, it is imperative that these children and their families receive comprehensive and individualized care.

Pediatric-focused advanced practice registered nurses (APRNs), including pediatric nurse practitioners (PNPs), play an essential role in the life of CYSHCN. They have

the education, knowledge, and skills to successfully lead, coordinate, and manage the complex care of CYSHCN (Martin-Misener et al., 2015). In addition, studies have demonstrated improved health outcomes and operational efficiencies along with decreased health care costs in APRN-centered multidisciplinary teams caring for CYSHCN (Donnelly, Shaw, Timoney, Foca, & Hametz, 2020). APRN's unique training focuses on holistic care—a vital component in caring for CYSHCN. Pediatric-focused APRNs deliver a variety of pediatric health-related services, including health promotion, health maintenance, management of both acute illness and chronic conditions, as well as sub-specialty care. While providing these services, APRNs create partnerships for family empowerment that support the physical and behavioral needs of children and adolescents while also promoting family strengths and well-being. Along with exceptional clinical care and coordination, pediatric-focused APRNs can serve as experts in the care of CYSHCN to their peers and colleagues while promoting effective communication between all members of the health care team (Ratna, 2019).

Care coordination is an essential element of a transformed American health care delivery system that emphasizes optimal quality and cost outcomes, addresses family-centered care, and calls for partnership across providers, settings, and communities (Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee, 2014). Studies support outstanding outcomes associated with care coordination performed by pediatric-focused APRNs within comprehensive care delivery models (Gresley-Jones, Green, Wade, & Gillespie, 2015). A randomized clinical trial (Mosquera et al., 2014) found striking reductions in both serious illnesses and health care costs when PNPs were involved in care coordination. Other studies continue to support the valuable role APRNs play in supporting care coordination within innovative care models and across various settings (Heuer & Williams, 2016; Moreno & Peck, 2020; Ruggiero, Pratt, & Antonelli, 2019).

With today's medical advances, 90% of CYSHCN are surviving into adulthood (Nehring, Betz, & Lobo, 2015), and therefore optimal transitional care is a critical component of their comprehensive health care. Historically, there have been multiple barriers to providing transitional care, including lack of formalized transitional programs and specialty and interdisciplinary adult providers to provide continuity of care and communication challenges between adult and pediatric providers (Nehring et al., 2015). To overcome these and other barriers, health care transition must begin in adolescence and will require ongoing collaboration between the CYSHCN, their families, and their interdisciplinary health care team both in pediatrics and adult care (Mahan, Betz, Okumura, & Ferris, 2017). APRNs, with their strong skills in patient and family education, communication, and care coordination, can be key role players to ensure the best outcomes during this challenging period for these youth.

Knowing the significant value of pediatric-focused APRNs in the care of CYSHCN, it is imperative that all legislation and policies related to the health care/medical home

include APRNs as reimbursable providers and full participants in demonstration projects, reimbursement strategies, and incentive programs. It is essential that legislation and policies are written with provider-inclusive terminology. Understanding the complex care model that best serves CYSHCN, further funding considerations should be taken to ensure the sustainability of the needed services. One example includes reimbursement for care coordination across all health care payer models (Cady, Bushaw, Davis, Mills, & Thomasson, 2020).

The National Association of Pediatric Nurse Practitioners (NAPNAP) affirms that:

- 1 Health care for CYSHCN should be family-centered, accessible, comprehensive, coordinated, culturally appropriate, compassionate, and focused on the overall well-being of children and families.
- 2 APRNs are uniquely qualified to provide high quality, cost-effective care to CYSHCN while facilitating multidisciplinary collaboration between members of the health care team.
- 3 Including pediatric-focused APRNs as part of a multidisciplinary team caring for CYSHCN has been shown to result in better health outcomes and increased family satisfaction (Samuels, Harris, Gonzales, & Mosquera, 2017).
- 4 Nurses can leverage initiatives to support the transformation of health care from an expensive, disease-based model to a cost-effective, quality-focused health management system (Ariosto et al., 2018).
- 5 APRNs serve as patient advocates to build partnerships with policymakers and create innovative, economical solutions for identified needs of families (Cleveland, Motter, & Smith, 2019).
- 6 Care coordination is a vital component of providing comprehensive care to CYSHCN and should be a reimbursable service for physicians and nonphysician practitioners, including APRNs.
- 7 Services should be provided in medical homes in which children's health records and plans of care are centralized, integrated into electronic health records, and accessible to families, with the capacity to be shared across systems with provision for patient privacy.
- 8 APRNs are proficient care coordinators and are qualified to lead health care/medical homes, provide primary direct health care, advocate for children and families, and make appropriate referrals.
- 9 Provider-inclusive language should be used in all legislation and policies regarding the care of CYSHCN.
- 10 Education regarding the comprehensive care of CYSHCN should continue to advance, with pediatric-focused APRNs in a leading role.
- 11 Advanced practice nursing students should receive education on complex care and should advocate for the addition of related learning objectives into certifying board standards.

In summary, NAPNAP is an organization whose mission is to empower pediatric-focused APRNs and key partners to optimize child and family health. NAPNAP believes that pediatric-focused APRNs, including PNP, are uniquely qualified to provide the level of care required for CYSHCN. As part of a multidisciplinary team, they serve as advocates and coordinators of care while leading in transformative health care for these youth and their families.

REFERENCES

- Ariosto, D. A., Harper, E. M., Wilson, M. L., Hull, S. C., Nahm, E. S., & Sylvia, M. L. (2018). Population health: A nursing action plan. *JAMIA Open*, *1*, 7–10.
- Cady, R., Bushaw, A., Davis, H., Mills, J., & Thomasson, D. (2020). Care coordination for children with medical complexity. *Nurse Practitioner*, *45*, 11–17.
- Cleveland, K., Motter, T., & Smith, Y. (2019). Affordable care: Harnessing the power of nurses. *Online Journal of Issues in Nursing*, *24*.
- Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. (2014). Patient- and family-centered care coordination: A framework for integrating care for children and youth across multiple systems. *Pediatrics*, *133*, e1451–e1460.
- Donnelly, S., Shaw, E., Timoney, P., Foca, M., & Hametz, P. (2020). Parents' assessment of an advanced-practice nurse and care coordination assistant model medical care coordination program for children with medical complexity. *Journal of Pediatric Health Care*, *34*, 325–332.
- Gordon, J. B., Colby, H. H., Bartelt, T., Jablonski, D., Krauthoefer, M. L., & Havens, P. (2007). A Tertiary care-primary care partnership model for medically complex and fragile children and youth with special health care needs. *Archives of Pediatrics and Adolescent Medicine*, *161*, 937–944.
- Gresley-Jones, T., Green, P., Wade, S., & Gillespie, R. (2015). Inspiring change: How a nurse practitioner-led model of care can improve access and quality of care for children with medical complexity. *Journal of Pediatric Health Care*, *29*, 478–483.
- Health Resources and Services Administration, Maternal and Child Health Bureau. (2020). *National survey of children's health*. Retrieved from <https://mchb.hrsa.gov/sites/default/files/mchb/Data/NSCH/nsch-data-brief.pdf>
- Heuer, B., & Williams, S. (2016). Collaboration between PNPs and school nurses: Meeting the complex medical and academic needs of the child with ADHD. *Journal of Pediatric Health Care*, *30*, 88–93.
- Mahan, J. D., Betz, C. L., Okumura, M. J., & Ferris, M. E. (2017). Self-management and transition to adult health care in adolescents and young adults: A team process. *Pediatrics in Review*, *38*, 305–319.
- Martin-Misener, R., Harbman, P., Donald, F., Reid, K., Kilpatrick, K., Carter, N., & DiCenso, A. (2015). Cost-effectiveness of nurse practitioners in primary and specialised ambulatory care: Systematic review. *BMJ Open*, *5*, e007167.
- McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., & Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, *102*, 137–140.
- Moreno, L., & Peck, J. L. (2020). Nurse practitioner-led telehealth to improve outpatient pediatric tracheostomy management in South Texas. *Journal of Pediatric Health Care*, *34*, 246–255.
- Mosquera, R. A., Avritscher, E. B., Samuels, C. L., Harris, T. S., Pedroza, C., Evans, P., . . . Tyson, J. E. (2014). Effect of an enhanced medical home on serious illness and cost of care among high-risk children with chronic illness: A randomized clinical trial. *Journal of the American Medical Association*, *312*, 2640–2648.
- Nehring, W. M., Betz, C. L., & Lobo, M. L. (2015). Uncharted territory: Systematic review of providers' roles, understanding, and views pertaining to health care transition. *Journal of Pediatric Nursing*, *30*, 732–747.
- Ratna, H. (2019). The importance of effective communication in healthcare practice. *Harvard Public Health Review*, *23*, 1–6.
- Ruggiero, K., Pratt, P., & Antonelli, R. (2019). Improving outcomes through care coordination: Measuring care coordination of nurse practitioners. *Journal of the American Association of Nurse Practitioners*, *31*, 476–481.
- Samuels, C., Harris, T., Gonzales, T., & Mosquera, R. A. (2017). The case for the use of nurse practitioners in the care of children with medical complexity. *Children*, *4*, 24.