

Financing Care for CYSHCN in the Next Decade: Reducing Burden, Advancing Equity, and Transforming Systems

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abstract

Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families (Blueprint for Change), presented by the Maternal and Child Health Bureau at the Health Resources and Services Administration, outlines principles and strategies that can be implemented at the federal and state levels and by health systems, health care providers, payors, and advocacy organizations to achieve a strong system of care for children and youth with special health care needs (CYSHCN). The vision for the financing of services outlined in the *Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and their Families* is one in which health care and other related services are accessible, affordable, comprehensive, continuous, and prioritize the wellbeing of CYSHCN and their families. There are several barriers caused or exacerbated by health care financing policies and structures that pose significant challenges for families of CYSHCN, including finding appropriate and knowledgeable provider care teams, ensuring adequate and continuous coverage for services, and ensuring benefit adequacy. Racial disparities and societal risks all exacerbate these challenges. This article outlines recommendations for improving financing for CYSHCN, including potential innovations to address barriers, such as state Medicaid expansion for CYSHCN, greater transparency in medical necessity processes and determinations, and adequate reimbursement and funding. Financing innovations must use both current and new measures to assess value and provide evidence for iterative improvements. These recommendations will require a coordinated approach among federal and state agencies, the public sector, the provider community, and the families of CYSHCN.

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Revising and restructuring the financing of services for children and youth with special health care needs (CYSHCN) is essential to achieve the vision of improved wellbeing and quality of life that is called for in the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB) *Blueprint for Change: Guiding Principles for a System of Services that Meet the Needs of CYSHCN and Their Families* (hereafter referred to as *Blueprint for Change*).¹ The financing of services underpins improving access, achieving equity, and integrating care across systems. Appropriate financing begins with comprehensive and continuous coverage for services to alleviate financial uncertainty for families. Beyond coverage in the current system, investments are needed to improve financing systems and integrate care. This paper articulates specific opportunities for the coverage of services and system investments that would be transformational for CYSHCN, their families, our communities, and the nation.

COVERAGE

Families of CYSHCN are responsible and directly provide care for their children with special needs in their own family settings. They face challenges in finding appropriate and knowledgeable provider care teams in addition to carrying the financial burden of the health care expenses needed by CYSHCN.² All of these aspects of achieving care have been complicated by the coronavirus disease 2019 pandemic in ways that have yet to be fully understood.^{3,4} Enrollment in insurance coverage, either public or private, is a necessary first step in accessing health care services. From 2016 to 2019, 49.4% of CYSHCN had employer-sponsored insurance, 38.9% had publicly

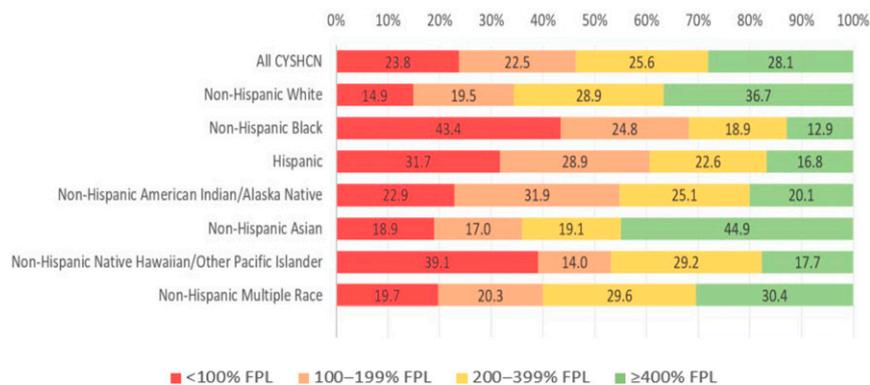


FIGURE 1 Families of CYSHCN, by race/ethnicity and poverty status, NSCH 2016 to 2019.

funded coverage, 7.8% had dual private/public coverage, and 4.0% were uninsured (unpublished analyses conducted by the Maternal and Child Health Bureau, Health Resources and Services Administration, 2018–2019 National Survey of Children’s Health). Insurance coverage is adequate for only 63% of CYSHCN.⁵ Insurance adequacy under public coverage (eg, Medicaid) is the most reliably robust of all sources, given the requirement under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit of coverage for all medically necessary services for enrollees under age 21.⁶ CYSHCN are disproportionately in or close to poverty compared with non-CYSHCN.⁵ Black, Indigenous, and Hispanic CYSHCN are more likely to be poor compared with White CYSHCN, as shown in Fig 1.

CYSHCN with household incomes >400% of the federal poverty level (FPL) have caregivers that report

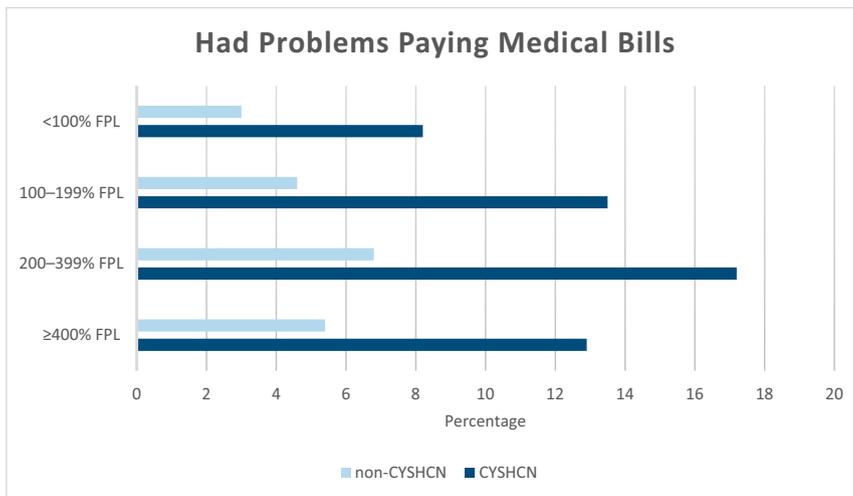
lower insurance adequacy (59.3%) than non-CYSHCN in the same income bracket (70.1%; Table 1). However, there is little to no gap in the adequacy of insurance for those with an income <100% of FPL (71.3% for CYSHCN vs 72.2% for non-CYSHCN) and those with an income of 100% to 199% of FPL (66.9% for CYSHCN vs 69.5% for non-CYSHCN). Many CYSHCN are covered by Medicaid or the Children’s Health Insurance Program (CHIP).⁷ For children enrolled in Medicaid and many children in CHIP programs at these income levels, full EPSDT benefits protect them from inadequate insurance coverage. For both private and public insurance options, state variation is also a contributing factor to benefit adequacy.^{8,9}

Having insurance coverage is insufficient to ensure the adequacy of all needed services. Recent National Survey of Children’s Health (NSCH) data reveal that one-third of CYSHCN have parents or caregivers report that their child’s

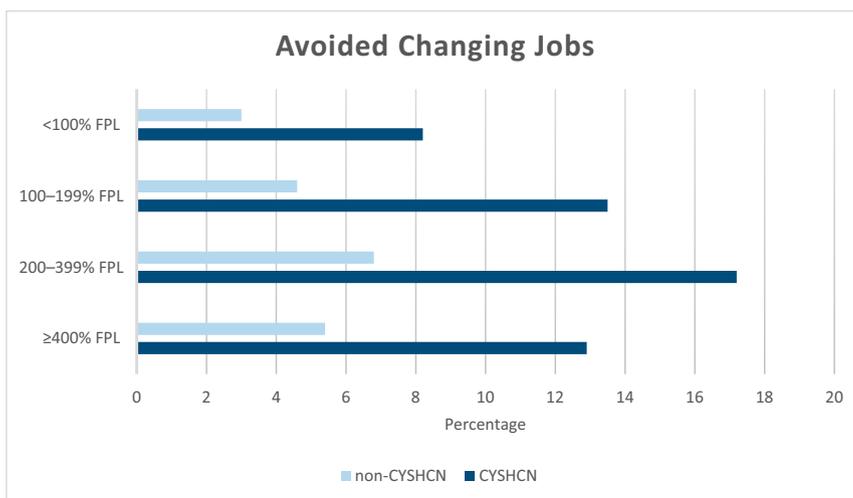
TABLE 1 Adequate and Continuous Insurance, by % of Poverty Level, NSCH 2016 to 2019

Adequate and Continuous Insurance Percentage (SE)			P
Poverty level	CYSHCN	Non-CYSHCN	—
<100% FPL	71.3 (1.5)	72.2 (0.9)	.31
100%–199% FPL	66.9 (1.6)	69.5 (0.8)	.07
200%–399% FPL	56.1 (1.2)	63.9 (0.6)	<.0001
≥400% FPL	59.3 (1.0)	70.1 (0.5)	<.0001

SE, standard error.



*All P values for CYSHCN and non-CYSHCN are significant at <.001 or higher.



*All P values for CYSHCN and non-CYSHCN are significant at <.0001.

FIGURE 2 Indicators of the Financing of Services for US CYSHCN, by Percent Poverty Level, NSCH 2016 to 2019.

coverage is inadequate based on 1 or more of the following criteria: (1) whether their children's insurance covers needed services,

(2) whether insurance allows the child to see the needed providers, and (3) whether it reasonably covers costs.¹⁰

CYSHCN compared with non-CYSHCN at all household income levels have parents or caregivers who are much more likely to report problems paying medical bills and more likely to have reduced employment or to not change jobs because of the loss of health insurance or other employee benefits (Fig 2). At all income levels, avoidance of changing jobs was at least twice as high for CYSHCN parents than for non-CYSHCN (Fig 2). A decrease in public insurance coverage for CYSHCN occurred from 2016 to 2019 (Table 2) with concurrent increases in difficulty paying medical bills and avoiding changing jobs to keep health insurance.

Service Systems

CYSHCN often interact with numerous service sectors. For example, in health care systems, these children and youth may need primary care, multiple specialty providers, and prescriptions. They also may need non-health related services such as social services, educational, and home- and community-based services to be able to thrive.¹¹ Yet support for the coordination of care between health care providers and the integration of care between health care and other sectors is often highly fragmented and, as a result, costly, which adds to families' burden of care.¹² Primary care, the component of the health care system directly responsible for care coordination and integration, is inadequately

TABLE 2 Trends in the Financing of Services for US CYSHCN, 2016 to 2019

	CYSHCN, % (SE)				non-CYSHCN, % (SE)			
	2016*	2017**	2018**	2019**	2016*	2017**	2018**	2019**
Type of insurance								
Public only	41.3 (1.1)	38.6 (1.7)	39.0 (1.3)	36.6 (1.2)	30.1 (0.6)	29.0 (0.9)	29.4 (0.7)	27.7 (0.7)
Private only	47.3 (1.0)	48.6 (1.6)	50.1 (1.3)	51.6 (1.3)	59.8 (0.6)	60.0 (0.9)	59.9 (0.7)	60.6 (0.8)
Had problems paying medical bills	15.8 (0.7)	18.9 (1.3)	16.4 (0.9)	18.2 (1.0)	8.8 (0.3)	8.7 (0.5)	8.1 (0.3)	9.5 (0.5)
Avoided changing job to keep health insurance	11.7 (0.7)	11.9 (0.9)	14.2 (0.9)	14.3 (0.9)	4.3 (0.2)	5.1 (0.4)	5.4 (0.3)	5.8 (0.4)

All P values for the CYSHCN and non-CYSHCN yearly estimates are significant at 0.0001 or <0.0001. (*, .0001; **, <.0001.) SE, standard error.

financed. This crisis in financing is felt most directly by CYSHCN and adults with chronic illness.^{13,14} The lack of these critical services is often worse during adolescence and through adulthood.¹⁵ During the pandemic, the lack of consistent and adequate funding for care coordination and successful telehealth services emerged as prominent challenges.¹⁶⁻¹⁸

State health officials are increasingly linking quality measures to alternative payment models that reward providers for delivering high-quality, cost-effective care.¹⁹ These initiatives are being tested in the public sector for Medicaid beneficiaries with chronic and complex conditions.^{20,21} Those measures that are feasible to collect are often important to systems but not directly relevant to families. There is a need for measures that support family-identified outcomes and wellbeing.²²

VISIONING THE FUTURE

As articulated in the HRSA/MCHB *Blueprint for Change*, financing a system of services for CYSHCN should achieve several straightforward goals. The first goal addresses the care itself. Families should be able to have care that does not present a financial burden but is also continuously available. In addition, families should have sufficient choice of services and administrative burdens should be low.²³ Second, financing systems should be oriented to address racial inequities and social risks that impact health and wellbeing. These systems should provide resources and mechanisms to strengthen communities and support families. When possible, services should be embedded in communities so they will be culturally appropriate. Third, service models should reward the value provided to

families and CYSHCN through new patient- and family-centered models of care that improve outcomes. These improved value-based models should also rejuvenate provider systems dedicated to the service of CYSHCN, whether they are primary care, community-based services, or integrators of care. Fourth, to be effective in achieving these goals, measurement systems will need to be revamped to integrate data and improve actionable feedback. Such measurement systems need to be flexible and improved continuously.

Achieving the vision for the financing of services requires broad collaboration among many parties, including public payors (Medicaid and CHIP) and private ones, including HRSA/MCHB and other agencies at the federal level and state programs, providers, and, most importantly, families, children, and youth, particularly those from diverse and underserved communities.

Recommendations and Opportunities for Innovation

This article offers several broad recommendations regarding direct improvements to the financing of services for CYSHCN. It includes recommendations for ensuring insurance access, improving coverage for medical care, and adequately funding all services in health and non-health systems.

1. The financing of child health should be conceptualized as a long-term investment rather than a time-limited cost.

To fulfill the vision for the future, specific actions will be needed. Mechanisms for public and private insurance coverage of care for CYSHCN should be improved while concurrently investing in

transformative system improvements. Federal investments to support state innovations in improved delivery models should set the direction for these efforts.

2. Mechanisms should be explored and developed at the federal level for states to optionally expand access to Medicaid for all CYSHCN. This expansion could be funded entirely or largely by the federal government and could include creating a reasonable, sliding scale, premium schedule for families at all income levels.

Mechanisms to ensure coverage adequacy now fall primarily on the public sector, with children often moving to the more comprehensive Medicaid EPSDT benefit. Among states, public sector coverage varies considerably on the basis of family income.²⁴ In addition, in states in which buy-in or waiver programs are available, CYSHCN must first receive disability designations to qualify for expanded benefits.^{25,26}

3. Coverage decisions should be based on the medical evidence provided and evaluated by experts to help achieve improved health outcomes, greater value, and cost-effectiveness. Requirements for transparent availability of criteria for the coverage of services must be applied to state Medicaid and private payor programs. Processes for determining individual authorizations for medical necessity should be transparent, and these processes should be monitored across the system. Assistance to support and educate families by families with similar experiences in navigating coverage requests and appeals should be provided.

Coverage for medical care supported by clinical evidence, thus demonstrating medical necessity, is essential for the wellbeing of CYSHCN. Families, youth, and children can make informed choices when medical evidence is presented and options are available based on that evidence. Greater education of providers and patients and their families around coverage criteria and medical necessity determinations also is essential to decrease the burden on families. Transparency of insurer processes should encompass obtaining authorization, understanding decisions, and requesting reconsiderations through appeals.

4. Payors should adequately fund long-term services and supports (LTSS), and specifically home- and community-based services, which often are central to the well-being of CYSHCN, to ensure that all eligible children can receive adequate services to meet their care needs. Funding should address the need to develop and support the LTSS workforce.

Children who rely on LTSS must have adequate access to these services and supports to ensure their optimal development and allow them to thrive at home as desired by the individual and family. Barriers to these services include the extensive waiting lists for LTSS through home- and community-based service waivers throughout the country, and workforce shortages that negatively impact access to these critical services even for those who have coverage.²⁷

5. Public and private payors should adequately fund primary care, care coordination, and care integration to ensure services

for all CYSHCN. Improved continuous service models, such as telehealth, should be supported with the aim of supporting models that improve coordination and integration, decrease family financial burden, and improve value to families and payors.

Integrated care delivery systems can improve the health and wellbeing of children and their families, and help avoid unnecessary medical, special education, and other costs.²⁸ During the coronavirus disease 2019 pandemic, new service models were developed to improve care and care planning for CYSHCN. Specifically, telehealth models can decrease family financial burden by reducing transportation costs for appointments, improving access for families that are not geographically close to primary and specialized services, and providing opportunities for more coordinated care.²⁹ With telehealth, care can transform from an episodic to a more continuous model.

Transforming Service Systems

Beyond the direct improvements to coverage noted in the first 5 recommendations, service systems should be further developed to achieve MCHB's *Blueprint for Change* vision for the financing of services.

6. Care coordination and care integration systems should be adequately funded to develop, test, and evaluate models and support their spread. These models should support families in diverse communities as well as children and youth with diverse special needs across all age transitions.

The spread of care coordination in the health care system and

integration between care systems requires adequate funding for the services that currently exist, as noted above. Concurrently, ongoing efforts will be needed to create and advance models that are truly integrated.

In 2019, Congress recognized this need for children with medical complexity who are covered by Medicaid and CHIP with the passage of the Advancing Care for Exceptional Kids Act.³⁰ The details of its implementation, including service models, measures, and payment models, have not yet been released.

Improved infrastructure to support integrated care coordination is needed to share resources and responsibilities in new ways. For example, financial structures should be developed to support integrated care planning and team-based communication among primary care providers, health care specialists, schools, and other service providers. In turn, funding mechanisms could support this blended work through cooperative agreements, service colocation, and care plans shared and integrated via electronic communication resources.

7. To address the unique needs of CYSHCN, financing systems that use value-based payment models that promote family-centered care, integration among physical health, behavioral health, and LTSS, and coordination within the intricate web of services spanning multiple sectors should be developed and implemented.

Value-based purchasing (VBP) models provide financial incentives to engage in care coordination, care integration, and population management activities that have the

potential to improve health outcomes.³¹⁻³³ These models link quality measures to payment that rewards providers for delivering high-quality and cost-effective care. VBP includes a broad range of financial models, from rewards for improvement on isolated quality measures to full financial risk accountable care. VBP programs offer the opportunity to promote innovative care delivery that potentially can address many gaps in care for CYSHCN.

The Centers for Medicare & Medicaid Services developed the Center for Medicare & Medicaid Innovation Integrated Care for Kids model to reduce expenditures and improve the quality of care for children <21 years of age covered by Medicaid.³⁴ Integrated Care for Kids is the first pediatric health care delivery model to be funded by the Centers for Medicare & Medicaid Services Center for Medicare & Medicaid Innovation, which funded almost \$126 million for 8 grantees within a 7-year model that began in 2020.³³

VBP requires the assessment of health and wellbeing outcomes for CYSHCN. Identifying and reporting on these outcomes can be difficult because of the heterogeneity of the CYSHCN population. Standardizing the assessment of outcomes must occur if they are to be fairly associated with financial rewards. In addition, measures that compensate providers via VBP can provide nuanced consideration of additional complexities related to social risk factors.^{35,36}

8. Community-based solutions to cover services provided in communities and the development of service infrastructure by the communities themselves should be adequately funded. Communities developing their

own system and processes can address equity, holistically support CYSHCN and their families, and add value to the health care system by engaging communities continuously in health system planning, implementation, and evaluation.

CYSHCN and their families may have social and economic needs that require resources and support from the community. Community participation as programs are being developed creates services more likely to successfully integrate social and medical needs. In some communities, this redesign could be seen as integrating health care systems into existing support programs. In other communities, programs could be initiated by the health care sector. For example, screening and the provision of services to address food insecurity could be initiated in the health care system, or screening could be integrated with resources from an existing program outside of that sector.

Supporting the development of a community-based workforce also is an essential component of this transformation. As addressed above in recommendation 4, adequate funding is needed to develop an LTSS workforce; in addition, workforce shortages constitute a barrier to CYSHCN accessing critical services.

9. Research organizations, federal agencies, and payors in collaboration with families, providers, and communities should develop accurate and reliable measures to enable effective monitoring and evaluation of system-level financial innovations. Measures of health care use, processes, and outcomes must be evaluated and improved.

10. Federal agencies should consider aligning measures already in production or in development across federal programs.

Measurement systems and specific indicators must provide value to families, children and youth, communities, and the health care systems that finance care. The proposed system innovations linking payment models to quality have the potential to build financial models that improve health and social outcomes for CYSHCN and their families. Measures should be linked to understanding the relationship of the cost of services to the quality of life, including the effectiveness of efforts to address social risk factors and racism. To achieve this goal, improved measurement is essential. Measurement includes developing and standardizing how to report utilization and quality measures across programs and systems. State and regional care systems, Title V programs, and Medicaid (both managed care and fee for service) require measurement that can be used to improve quality and analyze variation between insurers and jurisdictions.

Measurement must expand to encompass a broader understanding of health and wellbeing. Families, communities, and providers need these measures to reflect the “lived experience” outcomes important to families and CYSHCN.³⁷

11. Payors, quality improvement programs, and other agencies should develop and fund timely and data-driven feedback as an essential part of quality improvement processes.

Results from health care and social service programs focusing on both child and family outcomes and system financial impacts must be

shared with providers, communities, and funders in a timely manner to support quality improvement cycles.

A successful measurement system must link data across programs in federal, state, and local agencies to support local quality improvement and track system progress. States, with the assistance of federal partners, must establish the legal framework and required agreements, templates for data sharing, and technical infrastructure to implement the linked model.³⁸

CONCLUSIONS

The financing recommendations in this paper represent policy opportunities to improve outcomes for CYSHCN. Specific financing opportunities for system transformation should be developed primarily at the policy level to improve practice and, hence, the wellbeing and quality of life for CYSHCN. In addition, some recommendations call for investments at the community level that traditionally have not been considered a priority.

Implementing these approaches will require a coordinated approach among federal agencies, state agencies (eg, public health, Medicaid, mental health, education), the provider community, diverse racial and ethnic communities, and families and CYSHCN. Importantly, for efforts to be transformative, they will need to be financially sustained and iteratively improved at both the practice and policy levels. Research embedded into these transformative financial processes has the potential to support and enhance implementation.

The vision of the *Blueprint for Change*, supported by the financial opportunities outlined here, provides a path to the transformation of services for CYSHCN. The intended result will be improved wellbeing and quality of life for CYSHCN and their families, reductions in disparities, equity in the health care system, and increased value for those investing financially in CYSHCN.

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ABBREVIATIONS

CHIP: Children's Health Insurance Program
CYSHCN: children and youth with special health care needs
EPSDT: Early and Periodic Screening, Diagnostic and Treatment
FPL: federal poverty level
HRSA: Health Resources and Services Administration
LTSS: long-term services and supports
MCHB: Maternal and Child Health Bureau
NSCH: National Survey of Children's Health
VBP: value-based purchasing

REFERENCES

1. 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
2. Data Resource Center for Child and Adolescent Health. NSCH 2018-19: average weekly time spent providing art-home health care. Available at: <https://www.childhealthdata.org/browse/survey/results?q=7941&r=1&g=807>. Accessed September 9, 2021

3. McMorro S, Gonzalez D, Alvarez Caraveo C, Kenney GM. *Urgent Action Needed to Address Children's Unmet Health Care Needs during the Pandemic*. Washington, DC: The Urban Institute; 2020
4. Children's Defense Fund. Statement: leading children's health groups urge lawmakers and administration to address troubling trends in children's uninsurance. Available at: <https://www.childrensdefense.org/2020/statement-leading-childrens-health-groups-urge-lawmakers-and-administration-to-address-troubling-trends-in-childrens-uninsurance/>. Accessed July 30, 2021
5. Ghandour RM, Hirai AH, Kenney MK. Children and youth with special health care needs: a profile. *Pediatrics*. 2022; 149(suppl 7):e2021056150D
6. Musumeci M, Chidambaram P. *How Do Medicaid/CHIP Children with Special Health Care Needs Differ from Those with Private Insurance?* San Francisco, CA: Kaiser Family Foundation; 2019
7. Musumeci M, Williams E. *Children with Special Health Care Needs: Coverage, Affordability, and HCBS Access*. San Francisco, CA: Kaiser Family Foundation; 2021
8. Center for Innovation in Social Work and Health. National Association of Community Health Workers launches at unity conference 2019. Available at: <https://ciswh.org/project/the-catalyst-center/financing-strategy/mandated-benefits/n>. Accessed July 30, 2021
9. Brooks T, Roygardner L, Artiga S, Pham O, Dolan R. *Medicaid and CHIP Eligibility, Enrollment, and Cost Sharing Policies as of January 2020: Findings from a 50-State Survey*. Washington, DC: Kaiser Family Foundation; 2020
10. Data Resource Center for Child and Adolescent Health. The Child & Adolescent Health Measurement Initiative. Survey: 2019-2020 National Survey of Children's Health (NSCH) data query. Available at: <https://www.childhealthdata.org/browse/survey/results?q=7888&r=1&g=807>. Accessed June 7, 2021
11. Antonelli R, McAllister J, Popp J. *Making Care Coordination a Critical Component of the Pediatric Health System: A*

- Multidisciplinary Framework*. New York: The Commonwealth Fund; 2009
12. Lucile Packard Foundation for Children's Health, Association of Maternal and Child Health Programs and the National Academy for State Health Policy. Standards for systems of care for children and youth with special health care needs. Available at: https://www.lpfch.org/sites/default/files/field/publications/standards_v2_0.pdf. Accessed June 8, 2021
 13. VanLandeghem K, Honsberger K, Bergman D, Bayer E; National Academy for State Health Policy. Lucile Packard Foundation for Children's Health. National care coordination standards for children and youth with special health care needs. 2020. Available at: <https://www.nashp.org/wp-content/uploads/2020/10/care-coordination-report-v5.pdf>. Accessed July 30, 2021
 14. Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014;133(5):e1451–e1460
 15. Butler SM. How the health system overlooks young adults with chronic conditions. *JAMA Health Forum*. 2021;2(6):e211685
 16. Dustman R. AAPC Knowledge Center. Payers ending telehealth expansion coverage. Available at: <https://www.aapc.com/blog/51962-payers-ending-telehealth-expansion-coverage/>. Accessed July 19, 2021
 17. Kichloo A, Albosta M, Dettloff K, et al. Telemedicine, the current COVID-19 pandemic and the future: a narrative review and perspectives moving forward in the USA. *Fam Med Community Health*. 2020; 8(3):e000530
 18. State Health & Value Strategies. Princeton University. Executive summary: tracking telehealth changes state-by-state in response to COVID-19. Available at: <https://www.shvs.org/health-equity/executive-summary-tracking-telehealth-changes-state-by-state-in-response-to-covid-19/>. Accessed July 30, 2021
 19. Normile B, VanLandeghem K, Agrawal A; National Academy for State Health Policy. State strategies for Medicaid quality improvement for children and youth with special health care needs. Available at: <https://nashp.org/wp-content/uploads/2017/11/MQM.pdf>. Accessed July 30, 2021
 20. Song PH, Xu WY, Chisolm DJ, et al. How does being part of a pediatric accountable care organization impact health service use for children with disabilities? *Health Serv Res*. 2019;54(5): 1007–1015
 21. Adirim T, Meade K, Mistry K; COUNCIL ON QUALITY IMPROVEMENT AND PATIENT SAFETY; COMMITTEE ON PRACTICE AND AMBULATORY MANAGEMENT. A new era in quality measurement: the development and application of quality measures. *Pediatrics*. 2017;139(1):e20163442
 22. Schiff JS, Antonelli RC. Measurement that matters—joy in the village! *Psychiatr Serv*. 2019;70(5):357
 23. Kuo DZ, Rodgers RC, Beers NS, McLellan SE, Nguyen TK. Access to services for children with special health care needs and their families: concepts and considerations for an integrated systems redesign. *Pediatrics*. 2022;149(suppl 7): e2021056150H
 24. Kaiser Family Foundation. Medicaid/CHIP upper income eligibility limits for children, 2000-2021. Available at: <https://www.kff.org/medicaid/state-indicator/medicaidchip-upper-income-eligibility-limits-for-children/?currentTimeframe=0&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed September 9, 2021
 25. Hirschi M, Walter AW, Wilson K, et al. Access to care among children with disabilities enrolled in the MassHealth CommonHealth Buy-In program. *J Child Health Care*. 2019;23(1):6–19
 26. Bachman SS, Comeau M, Dworetzky B, Hamershock R, Hirschi M. The Louisiana Family Opportunity Act Medicaid Buy-in Program. *Matern Child Health J*. 2015; 19(12):2568–2577
 27. Kaiser Family Foundation. Medicaid HCBS waiver waiting list enrollment, by target population. Available in: <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colld%22:%22Location%22,%22sort%22:%22asc%22%7D>. Accessed September 9, 2021
 28. Marcu MI, Knapp CA, Brown D, Madden VL, Wang H. Assessing the impact of an integrated care system on the healthcare expenditures of children with special healthcare needs. *Am J Manag Care*. 2016;22(4):272–280
 29. Silow-Carroll S, DuPlessis H, Henry E, Di Paola S. Lucile Packard Foundation for Children's Health. COVID-19 policy flexibilities affecting children and youth with special health care needs. Available at: <https://www.lpfch.org/publication/covid-19-policy-flexibilities-affecting-children-and-youth-special-health-care-needs>. Accessed October 18, 2021
 30. Children's Hospital Association. Everything you need to know about the ACE Kids Act. Available at: <https://www.childrenshospitals.org/Issues-and-Advocacy/Children-With-Medical-Complexity/Talking-Points/ACE-Kids-Act-Resource-Center>. Accessed September 1, 2021
 31. Crook HL, Zheng J, Bleser WK, Whitaker RJ, Masand J, Saunders RS. *How Are Payment Reforms Addressing Social Determinants of Health? Policy Implications and Next Steps*. New York: Milbank Memorial Fund; 2021
 32. Lipson DJ, Au M, Stringer R, Vogt R. Medicaid 1115 Demonstrations. Accelerating the adoption of value-based payment in Medicaid by linking delivery system reform to managed care payment. Available at: <https://www.medicaid.gov/medicaid/downloads/accel-adoption-vp-pay.pdf>. Accessed September 9, 2021
 33. Cattel D, Eijkenaar F. Value-based provider payment initiatives combining global payments with explicit quality incentives: a systematic review. *Med Care Res Rev*. 2020;77(6):511–537
 34. Centers for Medicare & Medicaid Services. Integrated care for kids (InCK) model. Available at: <https://innovation.cms.gov/innovation-models/integrated-care-for-kids-model>. Accessed April 28, 2021
 35. Nerenz DR, Austin JM, Deutscher D, et al. Adjusting quality measures for social risk factors can promote equity in health care. *Health Aff (Millwood)*. 2021; 40(4):637–644
 36. 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
37. Coleman, CL, Morrison M, Perkins SK, Brosco JP, Schor EL. Quality of life and well-being for children and youth with special health care needs and their families: a vision for the future. *Pediatrics*. 2022;149(suppl 7): e2021056150G
38. Academy Health. The Medicaid outcomes distributed research network (MODRN). Available at: <https://www.academyhealth.org/MODRN>. Accessed August 10, 2021