

Health literacy and the Affordable Care Act: a policy analysis for children with special health care needs in the USA

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Abstract: Children with special health care needs (CSHCN) represent populations with chronic health conditions that are often high utilizers of health care. Limited health literacy has emerged as a key indicator of adverse health outcomes, and CSHCN from limited health literacy families are particularly vulnerable. The purpose of this policy analysis is to outline key provisions in the Affordable Care Act (ACA) that incorporate health literacy approaches for implementation and have implications for CSHCN in the USA. Several key provisions are incorporated in the ACA that involve health literacy and have implications for CSHCN. These include: expansion of public insurance coverage and simplifying the enrollment process, provisions assuring equity in health care and communication among all populations, improving access to patient-centered medical homes that can offer care coordination, ensuring enhanced medication safety by changing liquid medication labeling requirements, and provisions to train health care providers on literacy issues. More research is needed to determine how provisions pertaining to health literacy in the ACA are implemented in various states.

Keywords: children, special health care needs, health literacy, Affordable Care Act, health policy

Children with special health care needs

Children with special health care needs (CSHCN) have been defined as those who have, or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health-related services beyond that required by children generally.^{1,2} It is estimated that nearly 13%–18% of children in the USA are CSHCN, yet they account for 40%–70% of all health care expenditures among children.^{1,3–6} While this definition includes many pediatric diagnoses over all demographic groups, there is an identified link between poverty and CSHCN.⁷

To date, most of the research regarding CSHCN in the USA has been limited to two large nationwide surveys that have described key access to care issues due to lack of coordination between primary and specialty providers, unmet needs regarding access to patient-centered medical homes, financial costs associated with caring for a child with special health care needs, and family-level disparities due to both direct medical costs and loss of days at work.^{1,2} During the past decade, significant steps have been taken to ensure health care coverage for CSHCN through programs like the Children's Health Insurance program (CHIP), Medicaid, and other policy-based state and federal programs; however, there is still a defined need for coordination of specialty and primary care providers and high-quality, family-centered approaches to care in this population.⁸ Over 33% of families of CSHCN report their health coverage is inadequate and

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places their family at financial risk.⁴ Most of these described challenges focus on inadequate access to medical specialists, inadequate coverage of wrap-around (ancillary) services, and unreasonable uncovered or out-of-pocket costs.⁴

Family-level attributes that predict successful clinical outcomes and high-quality care among CSHCN are substantially less understood and represent a defined gap in the literature. Of these family-level attributes, caregiver health literacy, or “the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions”, has been identified as a key predictor of child health outcomes and health care utilization.^{9,10}

Health literacy and the Affordable Care Act

Health literacy is recognized by the Institute of Medicine as an integral component of high-quality health care and it is estimated that 36% of all adults in the USA have limited health literacy; the prevalence increases to around 50% among those who are also from a low income background.⁹ In pediatric populations, it is estimated that one in three caregivers/parents has limited or marginal literacy skills, meaning that they have difficulty using complex texts to accomplish everyday tasks and lack the skills necessary for full participation in health care settings.^{10,11} Limited health literacy families have not been well studied in pediatric populations with complex illnesses, such as CSHCN.¹² Despite the fact that CSHCN have varied treatment trajectories, prolonged periods of hospitalizations, and complicated home medication regimens, there is little information available on the role that limited health literacy has on long-term clinical outcomes, such as successful chronic disease management, health care utilization, and adherence to medical recommendations. Additionally, very few studies have evaluated the relationship between the health literacy and health service use of caregivers and access to coordinated services among their children, even though these relationships have been established in several adult populations.¹²

While salient research questions remain to be answered within the context of health literacy among families of CSHCN, there are also many direct policy linkages that persist among this population. The passing of the Patient Protection and Affordable Care Act (ACA) has led to extensive reforms that impact families of CSHCN, most notably regarding expansion of Medicaid and CHIP eligibility that is still in the process of being interpreted and implemented at the state level.¹³ While increasing access to health care

coverage and reducing gaps in Medicaid eligibility should be applauded, the ACA also has direct and indirect policy provisions that include health literacy, which have not yet been examined. The purpose of this policy analysis is to identify and discuss key provisions in the ACA that incorporate health literacy approaches and have direct implications for CSHCN and their families. A policy discourse analysis was conducted among primary sources of data from the ACA¹⁴ as well as secondary data sources, including white papers from health literacy and child health advocacy groups, commentaries from medical journals, and textual data on blog sites from lay health consumers.

Provisions of the Affordable Care Act with health literacy applications

Health literacy is directly mentioned in four sections of the ACA (Table 1). These provisions include: dissemination of research regarding health care quality measures, enhancing shared decision-making strategies, proposed advocacy regarding changes in medication labeling, and workforce development inclusive of health literacy strategies.¹⁵ Possible benefits and positive outcomes of these provisions for CSHCN are presented in Table 1.

There are several key areas where indirect provisions of the ACA could have health literacy implications for CSHCN (Table 2). These content areas include: extending health insurance coverage, innovations in quality, delivery and cost of care, workforce development, and health information strategies. The ACA sections, key defining components, and health literacy implications for CSHCN are also presented in Table 2.

Implementation considerations

In regards to health literacy-specific programming and evaluation, the ACA is not a strong legislative change agent for health literacy inclusion or health literacy-specific reforms. Most notably, the legislative language alludes to health literacy in several key areas, but it is mentioned within a consultative model only, without any regulatory mandates or associated financial provisions. None of the direct mentions of health literacy include it within the scope of health literacy-specific programming. Especially disappointing within the context of nursing care delivery and nursing education is the lack of health literacy inclusions in workforce development strategies, which could include primary care nurse practitioners (both family and pediatric) or pre-licensure education of registered nurses, but only include physicians. The workforce development areas were allocated \$125 million in the form

Table 1 Direct mentions of health literacy in the Affordable Care Act

Section	Title	Provision	Possible outcomes for CSHCN	Program vs consultation
3501	Health Care Delivery, System Research, Quality Improvement Technical Assistance	Research from AHRQ's Center for Quality Improvement and Patient Safety be made "available to the public through multiple media and appropriate formats to reflect the varying needs of health care providers and consumers and diverse levels of health literacy."	More transparency regarding quality outcomes in children's hospitals and pediatric primary care and specialty care settings.	Consultation with health literacy experts
3506	Program to facilitate shared decision making	Amends the Public Health Service Act to authorize a "program to update patient decision aids to assist health care providers and patients." (Administered by the CDC and NIH to develop, update, and produce patient decision aids for preference-sensitive care to assist providers in educating patients and caregivers regarding efficacy and cost of treatment and palliative approaches. "Decision aids must reflect varying needs of consumers and diverse levels of health literacy.")	Decision aids could be developed for limited health literacy families or to help engage in shared decision-making – both for treatment decisions and for decisions at the end of life for CSHCN with life-limiting diagnoses.	Consultation with health literacy experts; section authorized but not funded
3507	Presentation of Prescription Drug Benefit and Risk Information	Determines whether the addition of information on drug labeling and print advertising will help consumers; to consult with various stakeholders and "experts in health literacy."	Proposes changes in drug labeling standards – in particular liquid medication – that could decrease medical error rates for limited literacy caregivers of CSHCN.	Consultation with health literacy experts. FDA currently leading studies, literature review and consultation. First report to Congress in 2011.
5301	Training in Family Medicine, General Internal Medicine, General Pediatrics and Physician assistant.	Amends Title VII of the Public Health Service Act to make training grants available to primary medical specialties that "provide training in enhanced communication with patients ... and in cultural competence and health literacy."	Potential to infuse health literacy as a key health concept in medical training for pediatricians and family medicine physicians who care for CSHCN.	Programmatic, direct \$ allocation \$125 million through 2014 for entire section

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Abbreviations: CSHCN, children with special health care needs; FDA, US Food and Drug Administration; CDC, Centers for Disease Control and Prevention; NIH, National Institutes of Health; AHRQ, Agency for Healthcare Research and Quality; vs, versus.

Table 2 Indirect provisions related to health literacy that could have implications for CSHCN in the Affordable Care Act

Content area/ACA sections	Components	Health literacy implications for CSHCN
Extending health insurance coverage (Sections 1002, 1103, 1311, 1413, 2715, 3306)	1. Individual mandate for health insurance coverage; 2. employer mandates; 3. regional/state exchanges; 4. expansion of Medicaid eligibility; 5. extending dependent coverage; 6. eliminating lifetime limits on coverage; 7. prohibiting the denial of coverage with children with pre-existing conditions; 8. regulation of annual dollar limits on insurance coverage	Simplify the CHIP and Medicaid enrollment process; 90 percent of states currently have readability guidelines for Medicaid enrollment documentation
Innovations in quality, delivery and cost of care (Sections 2703, 3011, 3012, 3013, 3014, 3015, 3021, 3501, 3502, 3506, 3510, 10331, 10333)	1. A national approach in establishing a federal inter-agency quality workgroup; 2. Changes in delivery through improved care coordination and patient-centered medical homes; 3. cost reduction through pay-for-performance strategies	Establish the medical home model of care for CSHCN and tailor services in medical home care delivery model for limited-literacy caregivers
Workforce development (Sections 5205, 5301, 5307, 5313, 5402, 5403, 5507, 5606)	1. Scholarships, grants, and loan repayment for health care professionals in primary care and mental health; 2. Offers continuing education for health professionals who serve minority, rural and other special populations; 3. Improves medical school curricula in the areas of cultural competency and interprofessional education	Advocate for health literacy training (incorporating the use of plain language, 'teach back' modalities, etc) as a required competency for those training in pediatrics
Health information (Sections 3305, 3503, 3507, 4205, 10328)	1. Standards for nutrition labeling; 2. Assess if changes are needed in the presentation of prescription drug information	Establish national standards for safe-use labeling of pediatric liquid medications

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Abbreviations: ACA, Affordable Care Act; CSHCN, children with special health care needs; CHIP, children's health insurance program.

of loans, grants, and loan repayments to recruit physicians and physician assistants into primary care, and the legislative language does highlight training in cultural competence and health literacy, but the direct money allocation is not health-literacy specific.

Opportunity exists within health sciences education to incorporate health literacy training that would include clinicians who directly interface with CSHCN in a variety of care settings. In a recent survey of pediatric providers, more than 75% reported no regular use of evidence-based communication skills, such as teach-back methodology, reducing medical jargon, and using drawings to enhance verbal communication.¹⁶ To fully realize the health-literacy specific goals outlined in ACA Section 5301 for pediatric providers, there should be specific coordinated efforts between the Department of Health and Human Services, Health Resources and Services Administration, and medical and nursing organizations to make health literacy training a required component of post-graduate training in child health and to disseminate evidence-based health literacy training modules for pediatric providers, trainees, and nurses.¹⁶

Another opportunity for enhanced safety of CSHCN falls under ACA Section 3507, which authorizes the Department of Health and Human Services to consider alternative strategies for medication labeling, inclusive of strategies for individuals with limited health literacy. The US Food and Drug Administration published its final report to Congress based on this provision in 2011. The report did not imply any large shifts in reporting strategies, delaying decisions until the consultation and empirical research is completed.¹⁷ Medication errors are more likely in families with limited health literacy skills, and previous research has demonstrated that errors associated with dosing of pediatric liquid medications are common.^{18–20} Yin et al²⁰ found that 23% of caregivers used non-standardized liquid dosing and nearly 68% were unaware of weight-based dosing for children. CSHCN often have complicated home medication regimens, and strategies that would change both non-prescription and prescription information and ease of dosing would potentially have a large impact on medication safety in this population.

Arguably the largest impact of the ACA for CSHCN focuses on the extension of health care coverage through expansion of Medicaid and CHIP eligibility, and the individual and employer health insurance mandates. There are at least nine million children in the USA who are uninsured, and of those, at least five million are eligible for public insurance through Medicaid or CHIP.²¹ Individual states are still in the process of determining whether to expand Medicaid.

They are also still interpreting and developing implementation strategies for state and federal exchanges, Medicaid managed care plans, and CSHCN-specific programming.^{22–24} While there is no direct language in the ACA regarding health literacy strategies to enhance enrollment for health care coverage, there is a need to promote strategies for enrollment that include families with limited health literacy. Previous research has demonstrated that the average Medicaid and CHIP applications and renewal applications range between 11th to 18th grade (despite recommended reading levels ranging between 5th and 6th grade), use font sizes below 12 point, and have crowded formatting and excessively high reading demands.^{25–28} Outreach strategies for enrollment in health care insurance coverage (both public and private) that incorporate alternative strategies for enrollment and resources for limited health literacy are critical for CSHCN families.^{29,30}

Unifying themes

Even with mediocre direct legislative language, there are many opportunities to incorporate best-practice strategies that include health literacy considerations and evidence-based models of care to improve health care access and delivery for CSHCN. Unifying themes are found throughout the ACA that include patient-centered care and quality health communication.¹⁵ Research has demonstrated that the children of limited literacy caregivers are at the greatest risk for low-quality and uncoordinated health care.¹⁶ Within the past decade, the American Academy of Pediatrics has defined the patient-centered medical home as the optimal model for delivery of primary care.^{31,32} The medical home model of care consists of the following: accessibility, family-centeredness, continuity, comprehensiveness, coordination, compassion, and cultural effectiveness.³² Patient-centered medical homes provide each patient with a provider who leads and integrates an interdisciplinary care team to facilitate care across various services and settings.³³ While development of the medical home model was directed toward delivery of care for all children, it is increasingly cited as the fundamental component of improved quality care delivery for CSHCN to need to coordinate between primary and specialty care providers.

The ACA did include direct provisions for use of the Medicare Shared Savings Program to broadly implement Accountable Care Organization (ACO) models, with the hope of aligning ACOs with the patient-centered medical home model (ACA Section 3022).³⁴ Thus, ACOs agree to be accountable for the overall care, costs, and quality of care for patients enrolled in their services. The financial

structure incentive payments are determined by comparing the organizations annual incurred costs to Centers for Medicare and Medicaid Services-established costs that are benchmarked against quality of care best practices.³⁴ Implementing the medical home model (particularly if administered within the context of an ACO) presents a unique opportunity to mitigate disparities associated with limited health literacy for CSHCN by: incentivizing health literacy workforce education within its system, making health information more accessible and easier to understand for patients and families, appropriate screening for limited health literacy families, facilitating health literacy quality improvement projects, and engaging families in shared decision-making.

It has been estimated that limited health literacy adds an additional 3%–5% of the total health care cost per year per individual with limited health literacy.³⁵ Thus, there is significant financial incentive for ACOs to mitigate the financial impact of limited health literacy among caregivers of CSHCN, particularly because they are already high utilizers of the health care system. To date, most of the research surrounding caregiver health literacy has focused on health promotion, and more research is needed to determine if there are meaningful ways to modify the social determinants of coordination of quality of care for CSHCN, with a particular focus on: coordination of specialist care, care delivery during periods of transition, information needs that persist among these families, medication adherence, and quality discharge planning from acute care settings. Medical homes represent an optimal strategy for implementing and testing how health literacy can be incorporated in this model of enhanced care delivery.

Conclusion

Health care providers who regularly provide care for CSHCN have a unique opportunity to provide leadership on implementation of key health provisions for improved quality of care among limited health literacy families of CSHCN in the USA. The existing legislative language in the ACA that includes health literacy is weak and primarily exists as a consultative (not programmatic) provision. However, incorporating health literacy strategies into patient-centered medical home models for CSHCN provides an exciting opportunity for health care providers. As the implementation of the ACA continues to unfold, additional policy and health services research is needed to determine how this legislation is interpreted, and the impacts (intended and unintended) of those interpretations in the various states.

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