Impacts of Healthcare Reform Platforms on Children with Special Healthcare Needs

Brittany St. John, OTR, MPH
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Abstract

Children with special healthcare needs (CSHCN) have complex and diverse healthcare needs that often result in high healthcare utilization. Variable health insurance, lack of care coordination, inconsistent coverage of necessary services such as therapy and durable medical equipment, and high utilization highlight the shortcomings of the current U.S. healthcare system. Further, out-of-pocket expenditures vary widely and may lead to inequitable financial burden for some families. Changes in healthcare policy have deep implications for the coverage and quality of care for CSHCN as well as the financial stability of family caregivers. Healthcare reform platforms should specifically consider the needs of CSHCN and ensure adequate coverage and support are in place to reduce emergency service utilization and improve health outcomes for these children.

Introduction

Children with special healthcare needs (CSHCN) represent 18.5% of children in the united states (US).[1] Defined as children who have or are at risk of developing a chronic physical, developmental, behavioral, or emotional condition, CSHCN include children with disabilities who are medically complex. CSHCN have complex and diverse healthcare needs that often include multiple medical and rehabilitation professionals, making them likely to be high users of health services. A large study using a nationally representative sample of US children found that CSHCN made twice as many physician visits, had more than four times the number of hospitalizations, and had as much as five times as many non-physician visits such as mental health and rehabilitation visits than their peers without special healthcare needs.[2] High rates of healthcare usage equate to high out of pocket cost and the need for care coordination and management.

Unmet Needs and a Fragmented Approach

In its current state, the US healthcare system is ill equipped to meet the needs of CSHCN. Healthcare coverage is widely variable with 38.8% of CSHCN receiving public insurance, 49.3% private insurance, and 7.6% a combination of public and private. The remaining 4.3% of CSHCN remain uninsured,[1] despite many qualifying for Medicaid coverage.[3] Among CSHCN who are covered by insurance, both public and private, a multitude of unmet medical needs persists as each state and private insurance provider defines what is and is not medically necessary for the child. Providers face unique referral, pre-authorization, and appeal processes for each insurance provider as well as inconsistent coverage and reimbursement of services. This high level of variability increases the likelihood of inequity in access to and quality of healthcare services received by CSHCN.

CSHCN are more likely to have unmet needs with relation to specialty care[4], mental health care[5], and dental care[6] as compared to children without special healthcare needs. These specialty services and complex medical needs are further complicated by the lack of consistent access to care coordination and communication between providers. The complexity and variability of the U.S. healthcare system often leaves care coordination between families and the multitude of providers for the child fragmented without easily accessible information or universal care plans.[7] When consistent care coordination is lacking, families are left to navigate care coordination as well as their additional caregiver responsibilities for their CSHCN. Effective care coordination can impact long term

health outcomes and reduce unnecessary healthcare utilization.[7]

The current US health system is unable to fully meet the needs of families with children with disabilities. Despite current ACA mandates of essential service coverage, gaps persist for CSHCN.[8] The complexity of needs and the variety in coverage and cost demonstrate that consistent, accessible, and affordable healthcare is a vital need for families of CSHCN and healthcare reform is necessary to adequately meet their needs.

Proposed Healthcare Reform Platforms

Healthcare reform is one of the leading political platforms for the 2020 presidential race. Three primary routes have been supported by candidates thus far; dismantle the affordable care act and lower healthcare spending, create a public healthcare option within the network of health insurance currently available, and Medicare for all or a complete socialized healthcare approach. Each of these platforms presents changes to healthcare coverage for CSHCN, most importantly changes to Medicaid, and present with strengths and weaknesses.

Dismantle the Affordable Care Act

Dismantling the ACA in the name of reduced spending has been the primary goal of the current administration in regard to healthcare reform. The foundation for this platform is a reduction in federal spending on healthcare and advocating for individual choice about health insurance coverage.[9] A replacement for the ACA is not presented, rather a series of reductions in ACA mandates and related funding are proposed as well as increased state autonomy in accepting or refusing Medicaid expansions.

A review of the proposed changes, the potential impacts on insurance coverage, and the federal deficit in the U.S. reveal that the proposal will have devastating impacts.[10] Uninsured individuals in the U.S. would drastically increase, with low-income and people with poor health disproportionately bearing the most burden.[10] In addition, the federal deficit is projected to increase from 500 million dollars based on the changes.[10]

Reductions in the ACA mandates based on proposed changes could have drastic impacts for CSHCN. Under the ACA, insurance coverage for CSHCN increased overall, and specifically increased coverage by mandating that children are eligible for coverage through age 26, essential health benefits are covered by all plans, and no child can be denied coverage based on utilization, cost, or pre-existing condition.[8] Reduction in any of these mandates would likely decrease insurance coverage or access to necessary services for CSHCN on public or private insurance plans. These changes would directly increase unmet healthcare needs and increase negative long-term outcomes.

One of the most significant proposed changes is the reform of block grant funding for Medicaid. States would have the option to forgo the current federal Medicaid funding structure in exchange for a fixed payment each year and significantly increased flexibility in the administration of Medicaid programs within their state. The proposed block grant changes are hailed as an opportunity for states to offer patients more benefits and control government spending simultaneously. However, the proposed changes could have dire consequences for CSHCN. States may opt to reduce rather than expand services covered, tighten the income qualifications for Medicaid, and increase out-of-pocket costs on enrollees.[11] Reductions in services covered are likely to impact CSHCN who have complex and varied needs, specifically as related to therapy services and specialist which are often services cut as “non-essential.” Further, CSHCN who do not meet qualifications for long term disability, such as children with cancer, may be covered by Medicaid due to family income. Restrictions in income coverage could mean loss of coverage for families and children. Finally, incurring increased out of pocket expenses will increase the burden for families with CSHCN, who are already at greater risk for financial stress.[12]

Public Healthcare Option

A popular incoming healthcare platform is the creation of a public healthcare option, allowing users to select Medicare coverage by choice. The implementation of a public healthcare option would replace ACA Medicaid expansions, and would specifically target prescription drug costs.[13] Foundationally this proposal aims to “build on” the ACA by expanding healthcare reform. However, it falls short of filling the gaps in our current system. A public healthcare option moves to increase federal spending by as much as $750 billion dollars, primarily aimed at increased subsidies for ACA enrollees.[14] States would be able to select from keeping their Medicaid expansion or replacing it with the public Medicare option, essentially guaranteeing that implementation will vary by

state, thereby creating amble opportunity for inequity.[13]

CSHCN are not as overtly impacted by this proposal as dismantling the ACA. However, the risks are high with several unknowns. Replacing Medicaid expansion with a public option may not guarantee full coverage replacement and the impact on uninsured CSHCN is undetermined. While likely lowering out-of-pocket costs for premiums, it is unclear how out-of-pocket costs for services will be changed. The proposal is vague at best and there are many unanswered questions. At the top of the list is how coverage will be equitable across states and how the option will impact rates of uninsured families? The public insurance option presents more unknowns than assurances and may include benefits and pitfalls impacting CSHCN.

Medicare for All

One of the most progressive platforms presented in this presidential race is a complete reform of the U.S. healthcare system to a single-payer Medicare for all approach.[15] Simply stated all private insurance and the healthcare system as we know it would be dismantled and restructured to support socialized care.[15] This proposal has the potential to resolve several of the shortcomings of the current healthcare system, mainly 100% of families and individuals would be insured and out-of-pocket costs including co-pays and co-insurance would be non-existent for covered and essential services. Costs for non-essential and elective services would persist but may be lower or determined on an individual basis. Medicare for all has the potential to greatly reduce the financial strain experienced by families of a CSHCN. Further, a systematic review and economic analysis found that a single-payer system likely saves money within the first year despite cries to the opposite.[16]

Some of the concerns related to single-payer systems may directly impact CSHCN. One of the most frequently cited concerns is that single-payer systems incur wait lists and delays in service. It is unclear how the current proposal aims to address this concern and it is worth continued exploration and attention. In addition, services that are deemed as non-essential may not be covered. Based on the 10 essential healthcare services as currently defined, CSHCN continue to have unmet healthcare needs specifically as related to dental care and rehabilitative therapy services.[4] Further clarification of the structure of the single-payer system is needed to truly analyze impacts on CSHCN. However, despite concerns noted previously it is likely to increase insurance coverage and reduce costs to families, thereby likely benefiting CSHCN.

In addition to addressing healthcare coverage and cost, a single-payer system greatly reduces the burden on families and providers to coordinate complex medical services for a CSHCN. A single healthcare system has the potential to unify documentation, care planning, referral processes, billing, and administrative coordination of care. Further, Care coordination has been shown to increase health outcomes as well as reduce costs[4,7] and it could be easily implemented as a component of the system to address the needs of medically complex individuals or high service users.

Summary

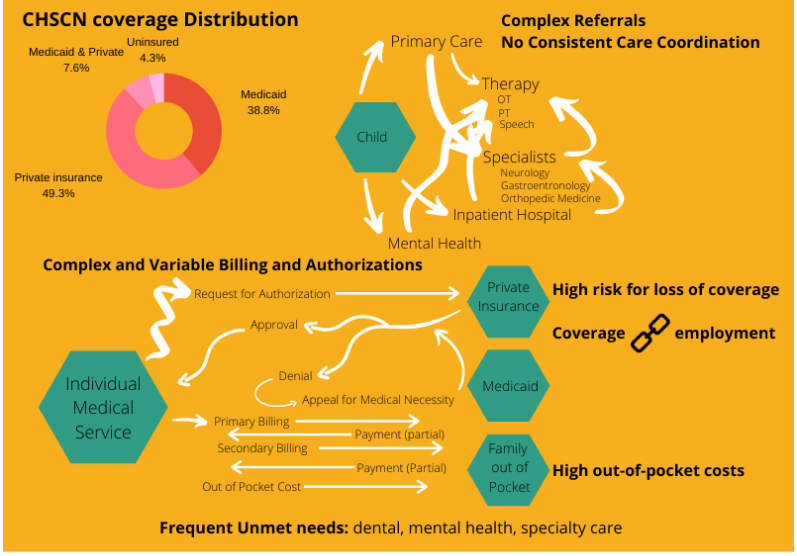
Currently, the US healthcare system is falling short of meeting the complex and variable medical needs of CSHCN. Any measure of healthcare reform will undoubtedly impact CSHCN, and their needs should be specifically considered when evaluating the impact and feasibility of a proposed platform. All currently proposed platforms have direct impacts on insurance coverage rates, out-of-pocket costs, and the federal deficit. Ranging from devastating increases in costs, uninsured rates, and disparities to achieving universal healthcare coverage with some possible complications, the proposals represent a wide range of views and values. Further, each proposal will directly impact access to health services and health outcomes for CSHCN. Within all of the currently presented healthcare platforms unmet needs and inequity for CSHCN and their families persists. For these reasons it is imperative that all healthcare reform proposals be evaluated carefully to ensure minimal harm and maximal benefit for all individuals, including CSHCN specifically. Rather than support a platform that is currently being offered, this paper recommends all healthcare reform be evaluated to assess impacts on CSHCN. What follows are two essential inclusions in any reform proposal. Without these two inclusions the complex and diverse needs of CSHCN will not be adequately or equitably met within the US healthcare system.

THREE POJECTED REFORMS OF

HEALTHCARE COVERAGE FOR CHIDLREN WITH SPECIAL HEALTHCARE NEEDS

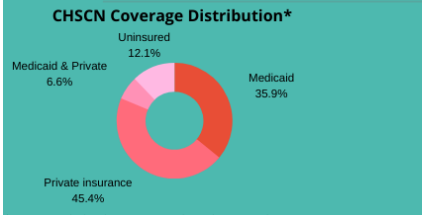
a comparison of systems

CURRENT SYSTEM



Frequent Unmet needs: dental, mental health, specialty care

1. DISMANTLE THE AFFORDABLE CARE ACT



*estimates calculated using estimated population % reductions in insurance coverage

- Uninsured/underinsured
- Coverage employment
- Family out of pocket cost
- Federal Deficit
- Complexity remains unchanged
- Care Coordination Possible

2. PUBLIC HEALTHCARE OPTION

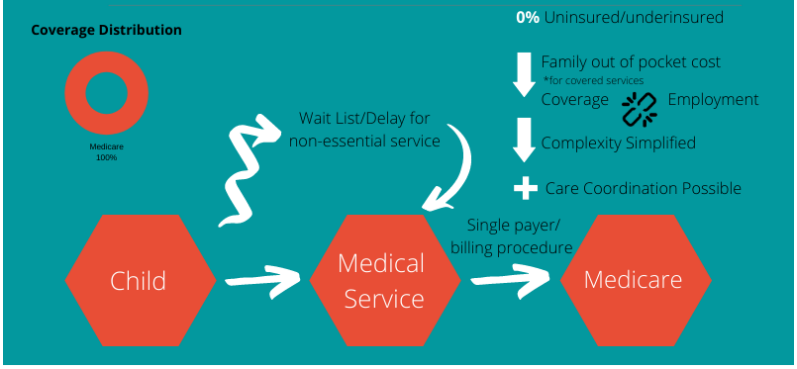
CHSCN Coverage Distribution*

UNKNOWN

- Impacts are hard to predict with vague proposal
- High potential for inequity in implementation

- Uninsured/underinsured
- Family out of pocket cost
- Federal Deficit
- Complexity likely remains
- Care Coordination Possible

3. MEDICARE FOR ALL



Recommendation 1: Healthcare reform must include comprehensive care coordination that is accessible and universal.

Comprehensive care coordination (CC) is absolutely essential to supporting families with CSHCN. CC is associated with benefits including reduced emergency department visits, reduced hospital charges, a decrease in missed appointments, increased likelihood of receiving a needed specialty service, decreased delay in accessing specialty services, fewer missed schooldays, increased family-centeredness of care, and overall increased family satisfaction with care.[17–22] One study identified that children receiving care coordination had an average hospital cost savings of $29,738 per patient equating to a 6.1% total reduction in hospital charges over the time period reviewed.[17] In addition to cost savings, children receiving CC had a reduction in length of hospital stay by almost half.[17] Further, a study looking at family outcomes from quality CC identified families have reduced out of pocket expenses, reduced financial burden and the percentage of parents who needed to reduce work hours or stop working to provide care was cut in half (from 40% to 20%).[19]

Despite evidence for cost savings, increased quality of care, and positive family outcomes, access to CC continues to be limited and inequitably distributed among families with CSHCN. In 2010, a study using the National Survey of Children with Special Health Care (NSCH) Needs found that 72% of families with CSHCN reported receiving some assistance with CC, yet only 55% of those receiving support reported it was adequate to meet their needs.[23] In 2016, a study using NSCH data found that 62.3% of CSHCN had access to CC.[24] Interestingly, Licthenstein and colleagues identified that CC rates were higher among uninsured families and those with lower education attainment.[24] The authors posit that this disparity may signify a stigma against the receipt of CC, which may present barriers to expansion of CC services. Despite this possibility, the benefits associated with the provision of comprehensive CC justify expansion of CC to all families with CSHCN.

Care coordination for CSHCN has a strong support base including promotion from the US Department of Health and Human Services Department of Maternal and Child Health, and the American Academy of pediatrics.[25,26] Families, providers, healthcare systems, and payers are all likely to benefit from implementation of a CC program. Healthcare reform must include the provision of comprehensive CC to meet the needs of CSHCN. A successful implementation of CC will be indicated by equitable and universal access to CC services, high family satisfaction with services, reduced emergency department usage by families with CSHCN, minimal need for families to reduce work for care needs and reduced financial burden for families.

Recommendation 2: Healthcare reform must include access to public insurance for all CSHCN regardless of family income or permanent disability status.

An estimated 4.3% of CSHCN are currently uninsured. Insurance coverage is essential to meet the medical needs of CSHCN and reduce reliance on emergency services. Any proposed healthcare reform platform must address the rate of uninsured CSHCN and eliminate potential gaps in insurance coverage. Currently, public insurance (Medicaid) is not accessible to all families. Families who qualify must meet long term disability qualifications that are more restrictive than qualification as a CSHCN or meet financial qualifications. An estimated 49% of CSHCN utilize private insurance, often connected to a parent's employment.[1]

Employment based insurance coverage is troubling for families with CSHCN as many parents have to reduce hours or leave work to complete caregiving responsibilities. An estimated 24% of families with CSHCN have experienced work loss due to the healthcare needs of their child.[27] A 2017 US study estimated the economic impact of family provided healthcare for CSHCN in forgone earnings to be $17.6 billion annually.[28] If a family were to face loss of insurance coverage due to changes or loss of employment, they may also experience an inability to access public insurance based on additional family factors. A public insurance option that is universally available to CSHCN would fill the gaps in insurance coverage as well as reduce the burden stemming from the balancing of employment dependent insurance with the healthcare needs of the child.

Access to public insurance would benefit more than the families themselves. Full insurance coverage of CSHCN will likely minimize the reliance of uninsured or underinsured families on emergency services, equating to cost savings for healthcare providers and systems. Analysis of universal public healthcare options continually demonstrate estimated cost savings for individuals and the

healthcare system.[16] Aside from cost reductions, additional metrics such as emergency service use, and insurance rates will indicate success of any reform attempt.

Summary

The recommendations presented above are strengthened by each other and will be most successful if implemented together. Both universal public insurance and CC have been associated with improved healthcare outcomes and lowered costs individually.[16,21,22] A universally accessible public insurance option for CSHCN paired with universally accessible CC will likely reduce unnecessary service utilization specifically as related to emergency services, minimize caregiving burden on families by reducing the amount of forgone earnings as well as the amount of caregiving a family is responsible for, and improve service delivery quality and efficiency. Paired implementation of these recommendations has positive implications for stakeholders across sectors and could contribute to efficient and effective healthcare reform that adequately meets the needs of CSHCN.

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