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Policy Brief

EMERGING CHALLENGES OF SERVING OHIO'S CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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INTRODUCTION

Children with special health care needs (CSHCN) are defined as “those who have or are at 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 by children generally.”¹ The report entitled “Emerging Challenges of Serving Ohio’s Children with Special Health Care Needs” used data from the 2012 Ohio Medicaid Assessment Survey (OMAS) and other sources to examine how Ohio’s CSHCN population is changing and consider how policy could respond to such changes. This document summarizes policy considerations generated by that report.

KEY FINDINGS

- Overall, 23% of children in Ohio have special health care needs, representing nearly 670,000 individuals ages 0-18 years old.
- Since 2008, Ohio’s CSHCN population has become larger and poorer. The number of CSHCN has increased by 11% (about 64,000 children), while the proportion living at or below 100% of the Federal Poverty Level (FPL) increased by 30%.
- Compared to children without special health care needs, CSHCN have worse reported health status, greater acute care utilization and more unmet needs. The magnitude of these differences has not changed significantly since 2008.
- CSHCN with functional limitations face especially significant challenges, such as having twice the odds of having unmet dental needs compared to CSHCN who only need prescriptions.

• CSHCN are no less likely than other children to receive care consistent with a patient-centered medical home.

• CSHCN covered by Medicaid tend to have greater needs and worse health status compared to those with other types of insurance or no insurance. Specifically, CSHCN with Medicaid are more likely to have functional limitations (32% vs. 23%) and fair/poor general health status (15% vs. 7%). They are also more likely to require inpatient hospital care (14% vs. 9%) compared to other CSHCN.

• Notably, even given these differences, CSHCN covered by Medicaid do not have more unmet health care needs compared to other CSHCN covered by employer-sponsored insurance.

KEY CONSIDERATIONS

Nearly one in five US children has special health care needs, yet those same children generate 40% of the health care expenses in their age group.^{2,3} Beyond their cost to the health care system, this population is important for policymakers because their disproportionate health care needs are associated with reduced work productivity for parents,⁴ higher rates of school absenteeism,³ and poorer health-related quality of life for children.⁵ State and federal health policy decisions have the potential to impact access to insurance, access to care, and the quality of care in this at-risk population. Specific policy considerations generated by this report are discussed below.



Changes in the Economic and Health Care Policy Landscape

The period between 2008 and 2012 was marked by significant changes in the economic and health care landscape. Economically, unemployment rates reached high levels not seen in decades. These job losses were associated with decreased access to employer-sponsored insurance and subsequent growth in the uninsured and publically insured populations.^{6,7} These economic challenges are reflected in changes in the CSHCN population in Ohio. Between 2008 and 2012, the proportion of CSHCN living in households at or below 100% of the poverty level increased by 31% (29% to 38%) and the proportions of CSHCN covered by Medicaid grew from 46% to 59%.

Although there are recent signs of stabilization in the economy, changes in the nature of employment (e.g. increased role of part-time and temporary work without health benefits) will likely lead to continued high rates of reliance on public or publically-subsidized health insurance coverage. The good news is that children covered by Medicaid fare no worse on measures of unmet health care need than those covered by employer-sponsored insurance, even though CSHCN covered by Medicaid are more medically complex. Two important policy questions, however, require further consideration. First, what policies are needed to ensure access to primary care and specialty providers (especially if Medicaid enrollment continues to grow due to policy or economic changes)? Second, will publically-subsidized health insurance exchanges be truly affordable for the working-class families not covered by employer-sponsored insurance?

Patient-Centered Medical Home

Patient-Centered Medical Home (PCMH) is a model of care that is patient-centered, comprehensive, coordinated, accessible, and focused on quality and safety. Our analyses found that only 36% of Ohio CSHCN met criteria for having care consistent with a medical home: having a usual source of care, having a personal doctor or nurse, having seen a physician in the past 12 months, and having access to specialist care and medical reminders as needed.⁸ We found that lack of care consistent with a medical home was significantly associated with reporting that care was harder to get than three years ago. Notably, however, we found no significant association between medical home status and unmet prescription medication, dental care, or other medical needs. PCMH was also not associated with differential use of well-child or emergency room visits. These results were surprisingly divergent from other studies that have examined the

influence of PCMH on care of CSHCN.^{9,10} One potential explanation is the fact that our definition of PCMH did not include measures of family-centeredness or cultural effectiveness that are often included in other studies.¹¹ Although our analyses did not find any association between having care consistent with a medical home and various key outcomes, recent research supports that continued focus in this area has the potential to impact primary care utilization,⁹ racial health disparities,¹² and transition planning.¹³ Therefore, we recommend continued investment in efforts to expand the number of certified PCMH's in the state.

Children with Functional Limitations

CSHCN are a diverse population. They can have health challenges ranging from mild asthma and seasonal allergies to severely disabling cerebral palsy and muscular dystrophy. Nationally, 3.2% of CSHCN are classified as “children with medical complexity” (CMC).¹⁴ These children not only need more services than the average child, they also have complex chronic conditions involving more than one organ system and/or require ongoing technical assistance (e.g., feeding tube, ventilator).¹⁵ Despite their small numbers, these children are a particular concern for multiple reasons: they are significantly more likely to have more than \$1,000 in annual out-of-pocket medical expenses, are more likely to have a family member stop working to provide care, and often have five or more unmet health care needs.^{15,16} Although, the detailed clinical data required to classify youths as CMC are not available in the OMAS, a drill-down analysis of the CSHCN reported to have functional limitations offers some insight into the challenges faced by our sickest CSHCN.

In Ohio, while the number of CSHCN increased between 2008 and 2012, the proportion of CSHCN with functional limitations remained fairly stable. In each year, just over one in four respondents reported that their child was “limited in doing the things most children of the same age can do.” Ohio CSHCN who have functional limitations are significantly more likely than other Ohio CSHCN to have unmet dental, and other medical needs. These findings suggest that children with functional limitations (including youth who meet the definition of “disabled”) could benefit greatly from Ohio's current policy initiative to move most youths covered by the Aged, Blind, and Disabled (ABD) program from fee-for-service coverage to managed care plans. Managed care and accountable care organizations have the potential to operationalize

the “medical neighborhood” model which facilitates the linkages between the PCMH and multiple subspecialists and social service providers.¹⁷ Many of these managed care organizations will, however, need targeted education on childhood disability issues to address a lack of familiarity with this challenged population. Close monitoring of health care access, utilization, and child health outcomes will also be important. Therefore, Ohio should also encourage the use of disability population-specific measures of health care quality to identify successes and opportunities for improvement.

Young Adults

As CSHCN age into adulthood, many experience new demands. Young adults with special health care needs (YASHCN) face particular challenges transitioning from parental health management to self-management and from pediatric to adult health care providers.¹⁸ Without such support, health status and disease management behaviors often deteriorate significantly in adolescence.¹⁹ *Healthy People 2020* has outlined provision of transition services for CSHCN to support their health care, work, and independent living. Yet nationally only 41% of teens meet the quality indicator standard for appropriate transition care.²⁰ As such, young adults with special health care needs are still an important area of interest for policy makers.

Differences between the adult and child OMAS questionnaires precluded any direct comparison between CSHCN and YASHCN findings. To be classified as a YASHCN, respondents, ages 19-25, needed to have functional limitations or need health care services greater than the average person their age. (Unlike in children, need for chronic prescription medication did not qualify young adults for special health care needs status.) This definition identified 12% of respondents, ages 19-25 as YASHCN, a rate much lower than the 23% found in children using the more complete definition.

Notably, 23% of YASHCN are uninsured, even after implementation of expanded dependent eligibility requirements for employer-sponsored coverage through the Affordable Care Act. An *ad hoc* drill-down analysis in this population showed that over 87% of the uninsured YASHCN had household incomes at or below 138% of the FPL. This fact is particularly relevant to ongoing policy considerations regarding extending Medicaid eligibility to most adults at or below this income level. Policy discussion should consider the fact that many low-income young adults who do not have access to employer-sponsored insurance (through their own employment or through

their parents) are limited in their insurance coverage options. Expansion of subsidized insurance, Medicaid or an equivalent, is needed to maximize health and minimize long-term costs in this population.

RECOMMENDATIONS FOR FUTURE RESEARCH

This analysis provides in-depth information on CSHCN, a vulnerable population in need of the focused attention of the health care system and health care policy makers. As always, the findings generated a number of new questions that could enhance our understanding of the population and provide additional support to the policy making process. Recommendations for future research are listed below.

Alignment across children, adolescents, and young adults – Our original analysis plan included comparing children, adolescents, and young adults with special health care needs. These comparisons were not possible because the health care needs on the adult questionnaire, completed by young adults, varied notably those on the child questionnaire. Future versions of the OMAS should consider aligning these items to facilitate comparisons. Survey designers should also consider adding a limited number of items measuring transition planning for adolescents who will be entering the adult health care system.

Clinical descriptions of CSHCN – Consistent with previous research, our definition of special health care needs was constructed based on needs for health and health-related services. A more complete profile would have also included information on the population’s clinical characteristics. Adding a list of common diagnoses to the OMAS questionnaire would allow grouped analysis by medical and behavioral diagnosis groups and would allow us to understand the underlying population health changes that are driving changes in the CSHCN rate.

Focused research on children with disabilities – As noted above, we were unable to do a detailed analysis of CSHCN with disabilities or children with medical complexity. Monitoring this population, as their payor type changes from fee-for-service to managed care, is imperative. Due to the small size of the population, the OMAS may not be the best vehicle for conducting said research. Instead, a longitudinal cohort study of children with disabilities could provide significant new knowledge regarding the relationship between changes in coverage models and health outcomes.

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More information about OMAS, including the data and electronic versions of reports and research briefs, is available online at: <http://grc.osu.edu/omas/>