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## House ACA Repeal Bill Puts Children with Disabilities and Special Health Care Needs at Severe Risk

By Jessica Schubel

The Senate is currently considering the American Health Care Act (AHCA) — the House-passed bill that would not only effectively end the Medicaid expansion, but radically restructure federal financing for virtually the entire Medicaid program, threatening coverage for tens of millions of Americans. These changes to Medicaid would make it especially hard for children with special health care needs, including those with disabilities, to get the care they need to stay healthy, remain in their communities, and succeed in life.

Medicaid provides affordable and comprehensive health coverage to over 30 million children, improving their health and their families' financial well-being.<sup>1</sup> In addition to the immediate health and financial benefits that Medicaid provides, children covered by Medicaid experience long-term health and economic gains as adults such as better health status, higher educational attainment, and greater earnings.<sup>2</sup> Medicaid plays an especially important role for children with special health care needs — including many children with private insurance who receive Medicaid “wrap-around” coverage to address gaps in their private coverage — by providing the services and supports they need on a daily basis.

The House-passed bill includes several changes that would harm children with special health care needs who rely on Medicaid. The House bill would:

- **Roll back Medicaid coverage for children ages 6 to 18.** The Affordable Care Act (ACA) raised Medicaid's minimum income eligibility limit for children from 100 to 133 percent of the poverty line, the level already in place for children under 6.<sup>3</sup> This change enables all children

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<sup>1</sup> Kaiser Family Foundation, “Insurance Coverage of Children 0-18 in 2015,” <http://kff.org/other/state-indicator/children-0-18/?dataView=1&currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.

<sup>2</sup> Sarah Cohodes *et al.*, “The Effect of Child Health Insurance Access on Schooling: Evidence from Public Insurance Expansions,” National Bureau of Economic Research, October 2014, <http://www.nber.org/papers/w20178.pdf>; David Brown, Amanda Kowalski, and Ithai Lurie, “Medicaid as an Investment in Children: What is the Long-Term Impact on Tax Receipts?” National Bureau of Economic Research, January 2015, <http://www.nber.org/papers/w20835.pdf>.

<sup>3</sup> When the ACA's 5 percent income disregard is applied, the effective income limit is 138 percent of the poverty line.

with family incomes below 133 percent of the poverty line — regardless of age — to be covered by Medicaid, a better coverage option for children with special health care needs than the Children’s Health Insurance Program (CHIP), which doesn’t cover some benefits these children need, such as special medical equipment and nursing care in their homes, and has out-of-pocket costs. The House plan would lower the eligibility level back to 100 percent of poverty, potentially affecting about 1.5 million children in 21 states.<sup>4</sup>

- **Radically restructure Medicaid’s federal financing.** The AHCA would fundamentally change Medicaid’s financing, ending the current federal-state financing partnership and converting virtually the entire Medicaid program to a per capita or block grant starting in 2020, putting coverage at risk for nearly 70 million people.<sup>5</sup> Converting Medicaid to a per capita cap or block grant would likely force states to increasingly cut eligibility and benefits, including long-term services and supports provided in beneficiaries’ homes and health services provided at school. These benefits are critically important to children with special health care needs.
- **Effectively end the Medicaid expansion.** While ending the Medicaid expansion doesn’t directly affect children, it jeopardizes their ability to maintain health insurance as they age into young adulthood — and ending expansion could cause their parents to lose health insurance, increasing financial instability for their families. It would also likely lead to a decrease in the number of eligible children enrolled in Medicaid as research shows that covering parents increases coverage for eligible but unenrolled children.

The emerging Senate bill reportedly retains all of these provisions.

## Medicaid Is a Critical Source of Coverage for Children with Special Health Care Needs

About 11.2 million children representing 15 percent of all children in the United States have special health care needs, such as autism, Down syndrome, cerebral palsy, depression, or anxiety.<sup>6</sup> These children often require specialized services and therapies to live a healthy life, such as nursing care to live safely at home, specialized medical equipment, or regular therapy to address physical, behavioral, or developmental illnesses and conditions, which most private insurance plans don’t cover.

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<sup>4</sup> Wesley Prater and Joan Alker, “Aligning Children’s Eligibility: Moving the Stairstep Kids to Medicaid,” Kaiser Commission on Medicaid and the Uninsured, August 2013, <https://kaiserfamilyfoundation.files.wordpress.com/2013/08/8470-aligning-eligibility-for-children.pdf>.

<sup>5</sup> Centers for Medicare & Medicaid Services, “Medicaid and CHIP March 2017 Application, Eligibility, and Enrollment Data,” May 17, 2017, <https://www.medicare.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>.

<sup>6</sup> Data Research Center for Child and Adolescent Health, “2009/10 National Survey of Children with Special Health Care Needs,” <http://childhealthdata.org/browse/survey/results?q=1792&r=1>.

The Department of Health and Human Services defines children with special health care needs as having “or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and also require health and related services of a type or amount beyond that required by children generally.” More information can be found here: <https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs#>.

Nearly three-quarters of children with special health care needs are in families with low or middle incomes.<sup>7</sup> Medicaid, along with other forms of public insurance, covers 44 percent of children with disabilities and special health care needs, serving as the sole source of coverage for over one-third of these children.<sup>8</sup> Medicaid also provides supplemental “wrap-around” coverage for many children with special health care needs who have private insurance, providing services not covered by private insurance and making the services they need affordable for their families.

## Several Pathways Connect Kids to Medicaid

Four main eligibility pathways allow children with disabilities and special health care needs to qualify for Medicaid. Two of these pathways are mandatory for states. The remaining two pathways are optional for states, allowing them to extend Medicaid eligibility to children with special health care needs who wouldn’t otherwise qualify because their family income exceeds eligibility limits.

- **Eligibility pathway #1: family income.** States must provide Medicaid coverage to all children with family incomes up to 133 percent of the federal poverty line. In addition, all states have elected to extend Medicaid or CHIP eligibility to cover children with family incomes above 133 percent of the federal poverty line.<sup>9</sup>
- **Eligibility pathway #2: Supplemental Security Income (SSI).** In most states, children with special health care needs who receive federal SSI benefits are automatically eligible for Medicaid.<sup>10</sup> While over 11 million children have special health care needs, few meet SSI’s strict eligibility standards. In fact, only 1.2 million children with special health care needs qualify for SSI benefits.<sup>11</sup> To qualify for SSI, children must live in families with low incomes and few assets and have a serious disability supported by medical evidence that limits their ability to function at home, school, and in the community.
- **Eligibility pathway #3: “Katie Beckett” option.** Nearly all states have expanded Medicaid eligibility to cover children with special health care needs who live in middle-class families. This optional pathway allows states to only count the child’s income, disregarding parental income and assets, just as they do for children living in institutions.<sup>12</sup> This makes it possible for children with special health care needs to qualify for Medicaid and remain at home to get

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<sup>7</sup> MaryBeth Musumeci, “Medicaid and Children with Special Health Care Needs,” Kaiser Family Foundation, January 2017, <http://kff.org/medicaid/issue-brief/medicaid-and-children-with-special-health-care-needs/>.

<sup>8</sup> *Ibid.*

<sup>9</sup> Tricia Brooks *et al.*, “Medicaid and CHIP Eligibility, Enrollment, Renewal, and Cost Sharing Policies as of January 2017: Findings from a 50-State Survey,” Kaiser Family Foundation, January 12, 2017, <http://kff.org/medicaid/report/medicaid-and-chip-eligibility-enrollment-renewal-and-cost-sharing-policies-as-of-january-2017-findings-from-a-50-state-survey/>.

<sup>10</sup> Most states automatically confer Medicaid eligibility on people who receive SSI; however, ten states have elected to use more restrictive eligibility criteria. These states are known as “209(b) states,” and include: Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia.

<sup>11</sup> Kathleen Romig, “SSI: A Lifeline for Children with Disabilities,” Center on Budget and Policy Priorities, May 11, 2017, <http://www.cbpp.org/research/social-security/ssi-a-lifeline-for-children-with-disabilities>.

<sup>12</sup> The income eligibility limits associated with this option are generally 300 percent of SSI, or 222 percent of the poverty line, with a \$2,000 asset limit.

care, rather than in a nursing home. (See Box 1.) To qualify, children must meet SSI medical disability criteria and their condition must require them to get care in an institution, such as a nursing home or hospital.

States have significant flexibility in how they implement this option: they can either establish their Katie Beckett program through their Medicaid state plan or through a home- and community-based services (HCBS) waiver. Regardless of how states set up their programs, they can target populations and tailor the long-term services and supports that they provide (e.g., case management, personal care, or respite services to children with autism, epilepsy, or cerebral palsy).<sup>13</sup>

Eleven states use their Medicaid state plan to implement their Katie Beckett programs.<sup>14</sup> These states cannot cap enrollment or impose a waiting list. However, most states — 27 states, including the District of Columbia — use HCBS waivers to implement their Katie Beckett programs. Like the Katie Beckett state plan option, HCBS waivers are optional for states, but provide them with more flexibility when designing their programs, including the ability to provide additional services that go beyond what Medicaid typically covers, cap enrollment, impose waiting lists, or charge premiums.<sup>15</sup>

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### Box 1: Katie Beckett's Legacy

When Katie Beckett was five months old in 1978, she contracted viral encephalitis, a brain infection, leaving her dependent on a ventilator to breathe. Medicaid covered Katie's care during her extended hospitalization, and she eventually was cleared to return home. A substantial barrier stood in her way — leaving the hospital would mean she'd lose her Medicaid coverage. At that time, parental income was counted when determining Medicaid eligibility for children living at home but not for children in institutions. This changed in 1981 when Katie's story caught the attention of President Reagan, who supported a waiver of Medicaid rules to allow children to get care at home by changing how parental income was counted. In 1982, Congress enacted a new Medicaid state option, permitting states to provide Medicaid to children without getting a waiver of federal rules. Although she passed away in 2012, Katie Beckett's legacy will continue — ensuring children with disabilities receive the care they need in the least restrictive and most cost-effective ways.<sup>a</sup>

<sup>a</sup> Joseph Shapiro, "Katie Beckett Defied the Odds, Helped Other Disabled Kids Live Longer," NPR, May 21, 2012, <http://www.npr.org/sections/health-shots/2012/05/21/153202340/katie-beckett-defied-the-odds-helped-other-disabled-kids-live-longer>.

- **Eligibility pathway #4: Medicaid “buy-in” option.** The Family Opportunity Act (FOA) option, established in the Deficit Reduction Act of 2005, allows children with special health care needs who reside in families with incomes up to 300 percent of the federal poverty line

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<sup>13</sup> Molly O'Malley *et al.*, "Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015," Kaiser Family Foundation, March 2016, <http://kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015-report/>.

<sup>14</sup> *Ibid.* This state plan option is also known as the Tax Equity and Fiscal Responsibility Act (TEFRA) option, which was established by Congress in 1982 as an optional Medicaid eligibility pathway.

<sup>15</sup> *Ibid.* Three states impose premiums in their Katie Beckett waiver programs: Arkansas, Connecticut, and Maine.

to “buy into” Medicaid. (Those with private coverage who buy in receive supplemental wrap-around benefits through Medicaid.) Children must meet SSI medical disability criteria, but unlike the Katie Beckett option, they don’t have to show they would otherwise need care in an institution. Five states use this option, with four of the five taking up the option to charge FOA participants premiums of up to 5 percent of family income.<sup>16</sup>

## **Medicaid’s Comprehensive Benefits Ensure Kids Get the Care They Need**

Medicaid is the gold standard for coverage of children with special health care needs, because it requires states to provide the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. Under this pediatric benefit, children and adolescents under age 21 have guaranteed access to a robust set of comprehensive and preventive health services, including regular well-child exams; hearing, vision, and dental screenings; and other services to treat physical, mental, and developmental illnesses and disabilities, such as speech and physical therapy and medical equipment and supplies. States must cover any medically necessary service that’s covered by Medicaid. Moreover, these services must be provided to children regardless of whether a state has elected to cover them for adults.<sup>17</sup>

The EPSDT benefit also includes long-term services and supports, a critical service for children with special health care needs. These services includes both institutional care, such as nursing home care, as well as personal care services and other services that help most children with special health care needs — 88 percent — get care in their homes.<sup>18</sup> Nearly all states and the District of Columbia also provide additional long-term services and supports that go beyond what Medicaid usually covers, such as habilitative and respite services, through HCBS waivers, which gives them additional flexibility to provide cost-effective long-term services and supports in the least restrictive setting — people’s homes.<sup>19</sup> These additional benefits, which can also include vehicle modifications and other support services, essentially wrap around the EPSDT benefit.

Medicaid’s EPSDT benefit also fills in coverage gaps for privately insured children with special health care needs. As of 2010, about half of children with special health care needs had private insurance.<sup>20</sup> However, over one-third of their families report that their private coverage is inadequate, meaning that they experience unmet needs for dental and mental health care, physical,

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<sup>16</sup> *Ibid.*

<sup>17</sup> States must provide both mandatory and optional Medicaid benefits specified in section 1905(a) of the Social Security Act.

<sup>18</sup> MaryBeth Musumeci and Katherine Young, “State Variation in Medicaid Per Enrollee Spending for Seniors and People with Disabilities,” Kaiser Family Foundation, May 1, 2017, <http://kff.org/medicaid/issue-brief/state-variation-in-medicaid-per-enrollee-spending-for-seniors-and-people-with-disabilities/>.

<sup>19</sup> Since 1981, when these waivers first became available, overall Medicaid spending on home- and community-based care has steadily increased, and in 2013, surpassed spending on institutional care. For more information on HCBS waivers, see Judith Solomon and Jessica Schubel, “Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community-Based Services,” Center on Budget and Policy Priorities, May 17, 2017, <http://www.cbpp.org/research/health/medicaid-cuts-in-house-aca-repeal-bill-would-limit-availability-of-home-and->

<sup>20</sup> Catalyst Center, “Expanding Access to Medicaid Coverage: The TEFRA Option and Children with Disabilities,” June 2015, <http://cahpp.org/wp-content/uploads/2016/02/TEFRA-policy-brief.pdf>.

occupational or speech therapy, and more commonly, long-term services and supports.<sup>21</sup> By providing wrap-around coverage, Medicaid ensures that privately insured children with special health care needs have the medically necessary services they need to remain in the community and stay healthy. Moreover, Medicaid relieves the significant financial burden that families of privately insured children with special health care needs often experience. Nearly 22 percent of families of children with special health care needs reported that their child's health condition caused financial hardship.<sup>22</sup>

## House Bill Jeopardizes Robust Coverage for Children with Disabilities and Special Health Care Needs

The AHCA would put children with special health care needs at particular risk of losing the critical health services Medicaid provides. The House-passed bill would do this by lowering Medicaid eligibility for children aged 6 to 18, radically restructuring how Medicaid is financed, and effectively ending the Medicaid expansion. (See Appendix Table 1.) Altogether, the House bill would result in 14 million fewer adults and children on Medicaid by 2026 and cut federal Medicaid spending by \$834 billion over the next ten years, according to the Congressional Budget Office.<sup>23</sup>

### Eligibility Rollbacks Would Make It Harder for Kids to Get Covered

Before the ACA, state Medicaid programs had to cover children under age 6 with family incomes below 133 percent of the poverty line and children aged 6 to 19 with family incomes below the poverty line.<sup>24</sup> The ACA eliminated this age difference, often referred to as “stairstep” eligibility, and required states to cover *all* children up to age 19 with incomes below 133 percent of the poverty line.

The AHCA would take a step backwards by reinstating stairstep eligibility, requiring that state Medicaid programs cover children aged 6 to 19 only up to 100 percent of the poverty line. Lowering the mandatory eligibility threshold could result in states switching coverage for these older children from Medicaid to separate state CHIP programs. This could cause many children with special health care needs to lose access to Medicaid's robust EPSDT benefit, which separate state CHIP programs don't cover. The risk of a Medicaid eligibility rollback would disproportionately affect older children as nearly 80 percent of children with special health care needs are over age 6.<sup>25</sup> (See Figure 1.)

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<sup>21</sup> Musumeci, *op cit.*

<sup>22</sup> Catalyst Center, *op cit.*

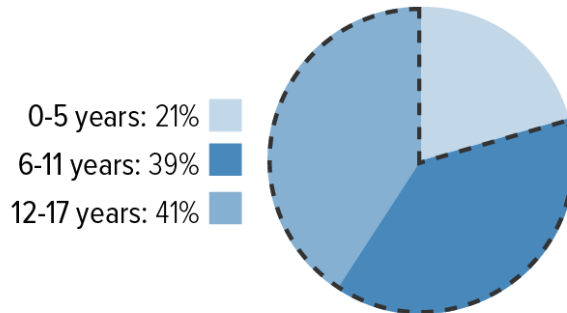
<sup>23</sup> Congressional Budget Office, “Cost Estimate: H.R. 1628 American Health Care Act of 2017,” May 24, 2017, <https://www.cbo.gov/system/files/115th-congress-2017-2018/costestimate/hr1628aspassed.pdf>.

<sup>24</sup> Kaiser Commission on Medicaid and the Uninsured, “Where Are States Today? Medicaid and CHIP Eligibility Levels for Children and Non-Disabled Adults,” March 2013, <https://kaiserfamilyfoundation.files.wordpress.com/2013/04/7993-03.pdf>.

<sup>25</sup> Musumeci, *op cit.*

FIGURE 1

## Most Children with Special Health Care Needs Are 6 or Older



Note: Percents may not sum to do rounding. Omits responses reported as “refused,” “don’t know,” or missing (<1%).

Source: National Survey of Children with Special Health Care Needs (2009-10)

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## Medicaid Per Capita Cap or Block Grant Would Lead to Loss of Coverage and Reduced Access to Needed Care

The AHCA would end Medicaid as we know it, ending the current federal-state financing partnership and converting virtually the entire Medicaid program to a per capita cap or block grant starting in 2020. Health care services for nearly all Medicaid beneficiaries would be subject to a per-beneficiary federal funding cap. In lieu of the per capita cap, states could elect to receive a block grant for children, adults other than seniors and people with disabilities, or both. Under the block grant option, states would get a fixed amount of federal funding regardless of the number of people they enroll. Both options would have devastating effects on children with special health care needs, as both a per capita cap and a block grant would shift significant costs and risks to states, with the cuts growing larger over time. To compensate, states would either have to raise taxes or cut other parts of their budget, or as is far more likely, make increasingly deep cuts to Medicaid eligibility, benefits, and provider payments.<sup>26</sup>

Under the block grant option, states would no longer have to provide certain benefits that are currently required. Children would likely be left with few federal protections related to their Medicaid coverage because states would no longer have to provide the guaranteed benefits they receive under EPSDT. This would be particularly harmful to children with special health care needs.

<sup>26</sup> For more on per capita caps, see Edwin Park, “Medicaid Per Capita Cap Would Shift Costs and Risks to States and Harm Millions of Beneficiaries,” Center on Budget and Policy Priorities, revised February 27, 2017, <http://www.cbpp.org/research/health/medicaid-per-capita-cap-would-shift-costs-and-risks-to-states-and-harm-millions-of>. For more on block grants, see Edwin Park, “Medicaid Block Grant Would Slash Federal Funding, Shift Costs to States, and Leave Millions More Uninsured,” Center on Budget and Policy Priorities, November 30, 2016, <http://www.cbpp.org/research/health/medicaid-block-grant-would-slash-federal-funding-shift-costs-to-states-and-leave>.

Families could also be charged potentially unlimited premiums, deductibles, and copayments for the services that their plans continued to cover.

Children in states subject to a per capita cap wouldn't fare any better. Under a per capita cap, states would receive a fixed amount for beneficiaries in the following eligibility groups: children, seniors, people with disabilities, non-expansion adults, and expansion adults. The per-beneficiary amounts would be set below projected Medicaid spending and would grow each year at a lower rate than expected health care costs.<sup>27</sup> States would ultimately receive less federal funding than needed to maintain coverage at current levels, forcing states to consider cutting eligibility, benefits, or provider payments — or, as is likely, all three.

One of the biggest threats the per capita cap model poses to children with special health care needs is that states would cut back on their use of the Katie Beckett and Medicaid buy-in options, states' two optional eligibility pathways. Under the AHCA's per capita cap and block grant proposals, the Katie Beckett and Medicaid buy-in options would be likely targets if states must make substantial cuts to their Medicaid programs due to federal funding shortfalls.

Losing Medicaid coverage would be devastating for families of children with special health care needs because of the potential impact on both the health of their children and the family's financial security. The Katie Beckett and Medicaid buy-in options allow parents to work without worrying that their child will lose Medicaid benefits. Without these options available to families, more parents would have to stay home to provide care. In 2010, 25 percent of families of children with special health care needs, including those with disabilities, reported that they cut back on hours worked or stopped working because of their child's health condition.<sup>28</sup>

The AHCA's per capita caps would also threaten Medicaid's important role in ensuring that children with special health care needs can get an education in the least restrictive setting. Medicaid pays for medical services, such as speech therapy and audiology, which are part of the special education plans for Medicaid-eligible children. In addition to paying for these critical health services, Medicaid helps schools by reducing special education and other health care-related costs, freeing up funding to help advance other initiatives. For example, many schools use Medicaid funding to pay the salaries of health care professionals at school, such as school nurses and therapists, or to implement programs that monitor the health care needs of eligible children with certain conditions, such as asthma and diabetes.<sup>29</sup>

By lowering Medicaid eligibility for older children, the AHCA would roll back coverage for children with special health care needs, making important health care services provided at school harder to get. Moreover, capping and cutting federal Medicaid funding, as the bill would do, would not only jeopardize the availability of health-related services in schools, but also hinder schools'

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<sup>27</sup> For more on how AHCA's per capita caps work, see Judith Solomon and Jessica Schubel, "Medicaid Cuts in House ACA Repeal Bill Would Limit Availability of Home- and Community-Based Services," Center on Budget and Policy Priorities, May 17, 2017, <http://www.cbpp.org/research/health/medicaid-cuts-in-house-aca-repeal-bill-would-limit-availability-of-home-and->

<sup>28</sup> Catalyst Center, *op cit*.

<sup>29</sup> For more information on Medicaid's role in schools, see Jessica Schubel, "Medicaid Helps Schools Help Children," Center on Budget and Policy Priorities, April 18, 2017, <http://www.cbpp.org/research/health/medicaid-helps-schools-help-children>.



ability to ensure that they have the appropriate health care staff on hand to provide such services as well as monitor the health needs of their Medicaid-eligible students.

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## **Box 2: Carving Out Populations Won't Fix Problems with Per Capita Caps**

Some proponents of per capita caps have recently suggested carving out children with special health care needs as a way to address concerns that these children could be harmed by capping federal Medicaid funding. A carve-out would fall short of protecting these children against the risks from capped federal funding. First, identifying children with special health care needs has been historically difficult for states, and would require significant investment to change state data systems to accurately track this population. Many children likely wouldn't be identified and would end up still being subject to the cap.

Second, no group can be protected by a carve-out because of how capped funding works. While the AHCA's per capita cap would establish separate funding caps for seniors, people with disabilities, children, other adults, and adult expansion enrollees, states would receive an overall amount of federal Medicaid funding that is the sum of the product of each population's per capita cap and actual enrollment in that eligibility group. This means that even if the cap amount for one group was adequate, a state would still face a substantial overall federal funding shortfall if the cap amounts for other groups were increasingly inadequate, forcing states to make cuts to eligibility, benefits, or provider payments that would affect their entire Medicaid programs. For example, House Republicans purported to protect seniors and people with disabilities by providing a "more generous" growth rate for the caps for those two groups starting in 2020 than the growth rate for children and other adults. But seniors and people with disabilities would still be subject to the eligibility and benefit cuts resulting from the overall inadequacy of the cap across all groups.

Even excluding entire populations or benefits from the cap would not protect those groups and services from cuts. For example, even though the House bill already excludes from the cap spending related to the Medicare Savings Programs (MSPs) — which provide help with Medicare premiums and cost-sharing for low-income Medicare beneficiaries — the MSPs would still be vulnerable to cuts that states would make in response to the per capita cap as a number of states have expanded the MSPs to serve more Medicare beneficiaries. As a result, no one can or will be protected from the large and growing Medicaid cuts states would have to make in response to the federal funding shortfalls under a per capita cap. For states to somehow shield seniors and people with disabilities, including children with special health care needs, while also balancing their budgets would require much deeper cuts to other children, parents, and working adults, who cost substantially less per beneficiary. Similarly, for states to shield children and parents, who make up the bulk of the Medicaid program, would require much deeper cuts to the relatively small number of seniors and people with disabilities, who have the greatest health and long-term care needs.<sup>a</sup>

<sup>a</sup> For more information on how per capita caps threaten coverage for everyone, see Hannah Katch, "House GOP Health Bill's Per Capita Cap Threatens Coverage for Everyone on Medicaid," Center on Budget and Policy Priorities, June 5, 2017, <http://www.cbpp.org/blog/house-gop-health-bills-per-capita-cap-threatens-everyones-medicaid-coverage>.

## **Ending Medicaid Expansion Would Leave Young Adults — and Parents — Without Coverage and Harm Families**

Thanks to the ACA's Medicaid expansion, adolescents with special health care needs now have a source of coverage as they transition into young adulthood. Before ACA, Medicaid typically didn't cover adults without children, leaving young adults with special health care needs nowhere to go once they aged out of Medicaid. Having a source of coverage as they age helps ensure young adults with special health care needs get the care they need, helps them engage in the community, and supports financial stability. The AHCA puts all this at risk as it effectively ends the Medicaid

expansion, leaving young adults who don't meet the SSI disability standard with few options for coverage.<sup>30</sup>

Young adults with special health care needs wouldn't be the only ones losing coverage. The ACA expanded coverage for millions of parents as many weren't eligible for coverage before ACA's expansion of Medicaid. Medicaid eligibility for parents pre-ACA varied considerably across states — the median pre-ACA eligibility level for working parents was 61 percent of the poverty line, and for unemployed parents, it was 37 percent.<sup>31</sup> Thirty-three states limited eligibility to less than the poverty line, with 16 states limiting eligibility to 50 percent of the poverty line.<sup>32</sup> By effectively ending the Medicaid expansion, the AHCA would force many of these parents back into the ranks of the uninsured. This would have harmful effects on children and parents alike.

Studies show that children are more likely to have health insurance if their parents are covered.<sup>33</sup> Losing coverage would mean children and their parents would go without needed medical care or that they would incur significant medical debt when they did seek care. For example, studies have shown that expanding Medicaid coverage results in fewer debts being sent to third-party collection agencies, and a recent *Health Affairs* study showed that the share of Medicaid expansion adults in Arkansas and Kentucky having trouble paying their medical bills dropped by 25 percent.<sup>34</sup>

## Conclusion

Medicaid plays a critical role in the lives of children with special health care needs by ensuring access to affordable health care services that they need to stay healthy and succeed in life. Faced with deep and growing cuts from a per capita cap or block grant, states would likely shut down pathways to Medicaid coverage for low- and moderate-income children with special health care needs and jeopardize their access to benefits that help them live at home and in their communities.

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<sup>30</sup> Young adults who meet the SSI disability criteria will continue to be covered under Medicaid's disability pathway. If the Medicaid expansion ends as proposed under the AHCA, young adults who don't meet the SSI criteria will no longer qualify for Medicaid as adults without children weren't eligible for Medicaid pre-ACA.

<sup>31</sup> Martha Heberlein *et al.*, "Getting in Gear for 2014: Findings from a 50-State Survey of Eligibility, Enrollment, Renewal, and Cost-Sharing Policies in Medicaid and CHIP, 2012–2013," Kaiser Family Foundation, January 2013, <https://kaiserfamilyfoundation.files.wordpress.com/2013/05/8401.pdf>.

<sup>32</sup> *Ibid.*

<sup>33</sup> Georgetown Center for Children and Families, "Healthy Parents and Caregivers are Essential to Children's Healthy Development," December 2016, <http://ccf.georgetown.edu/wp-content/uploads/2016/12/Parents-and-Caregivers-12-12.pdf>.

<sup>34</sup> Matt Broaddus, "Medicaid Improves Financial Well-Being, Research Finds," Center on Budget and Policy Priorities, April 28, 2016, <http://www.cbpp.org/blog/medicaid-improves-financial-well-being-research-finds> and Benjamin Sommers, *et al.*, "Three-Year Impacts Of The Affordable Care Act: Improved Medical Care And Health Among Low-Income Adults," *Health Affairs*, May 2017, <http://content.healthaffairs.org/content/early/2017/05/15/hlthaff.2017.0293>.

APPENDIX TABLE 1

**House Bill Would Restrict Children’s Access to Medicaid Coverage in Every State**

	<b>Katie Beckett State Plan Option</b>	<b>HCBS Waiver Comparable to Katie Beckett</b>	<b>Family Opportunity Act Buy-In</b>	<b>Eligibility Rollback for Kids</b>
Alabama		X		X
Alaska	X			
Arizona		X		X
Arkansas		X		
California		X		X
Colorado		X	X	X
Connecticut		X		
Delaware	X			X
District of Columbia		X		
Florida		X		X
Georgia	X			X
Hawaii		X		
Idaho	X			
Illinois		X		
Indiana		X		
Iowa		X	X	
Kansas		X		X
Kentucky		X		
Louisiana		X	X	
Maine		X		
Maryland		X		
Massachusetts	X	X		
Michigan	X	X		
Minnesota	X			
Mississippi	X	X		X
Missouri		X		
Montana		X		
Nebraska	X	X		
Nevada	X			X
New Hampshire	X			X
New Jersey		X		

APPENDIX TABLE 1

**House Bill Would Restrict Children’s Access to Medicaid Coverage in Every State**

	<b>Katie Beckett State Plan Option</b>	<b>HCBS Waiver Comparable to Katie Beckett</b>	<b>Family Opportunity Act Buy-In</b>	<b>Eligibility Rollback for Kids</b>
<b>New Mexico</b>		X		
<b>New York</b>		X		X
<b>North Carolina</b>		X		X
<b>North Dakota</b>		X	X	X
<b>Ohio</b>		X		
<b>Oklahoma</b>	X	X		
<b>Oregon</b>		X		X
<b>Pennsylvania</b>		X		X
<b>Rhode Island</b>	X			
<b>South Carolina</b>	X			
<b>South Dakota</b>	X			
<b>Tennessee</b>				X
<b>Texas</b>		X	X	X
<b>Utah</b>		X		X
<b>Vermont</b>	X	X		
<b>Virginia</b>		X		
<b>Washington</b>		X		
<b>West Virginia</b>	X	X		X
<b>Wisconsin</b>	X			
<b>Wyoming</b>		X		X

Notes: **Katie Beckett State Plan:** States that disregard parental income in determining Medicaid eligibility for children with significant disabilities who live at home and would be Medicaid-eligible if institutionalized; **Katie Beckett Waiver:** States that have elected to use a home- and community-based services waiver to disregard parental income in determining Medicaid eligibility for children with significant disabilities who live at home and would be Medicaid-eligible if institutionalized; **Buy-in:** States that allow people with disabilities who work and have incomes above Medicaid limits to buy into Medicaid; **Eligibility:** States that would potentially be affected by the change in Medicaid eligibility for children.

Sources: Molly O’Malley Watts, Elizabeth Cornachione, and MaryBeth Musumeci, “Medicaid Financial Eligibility for Seniors and People with Disabilities in 2015,” Kaiser Family Foundation, March 1, 2016, <http://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-in-2015-report/>; Jessica Schubel, “Little Noticed Medicaid Changes in House Plan Would Worsen Coverage for Children, Seniors, and People with Disabilities and Increase Uncompensated Care,” Center on Budget and Policy Priorities, March 15, 2017, <http://www.cbpp.org/research/health/little-noticed-medicaid-changes-in-house-plan-would-worsen-coverage-for-children>