

Testimony of

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Before the

Committee on Energy & Commerce, Subcommittee on Health

U.S. House of Representatives on “Legislative Proposals to Support Patients with Rare  
Diseases”

February 29, 2024

Chairwoman McMorris Rodgers, Ranking Member Pallone, and distinguished members of the Committee: Thank you for the opportunity to participate in this hearing to discuss H.R. 4758, Accelerating Kids' Access to Care Act.

The Accelerating Kids' Access to Care Act has strong bicameral bipartisan support, and as an Iowan I am so proud that Iowa Congresswoman Miller-Meeks along with Congresswoman Trahan of Massachusetts, are the House co-sponsors of the legislation.

This legislation will improve children's access to essential health care, while eliminating administrative burdens for families, providers and states. For children of Iowa and from across the United State, I ask you to join with your colleagues and support passage of the Accelerating Kids' Access to Care Act this year.

My name is Dr. Alex Bassuk. I am a pediatric neurologist, physician scientist, and The University of Iowa Department Chair of Pediatrics and Departmental Executive Officer, and the Physician-in-chief of our University of Iowa Stead Family Children's Hospital. Our mission at The University of Iowa and our Stead Family Children's Hospital is to improve the health of children through investigating new cures and treatments, teaching the next generation of pediatricians and pediatric scientists, and providing excellent clinical care for children and their families.

I am a member of The Association of American Medical School Pediatric Department Chairs (AMSPDC), The American Academy of Pediatrics (AAP), and our hospital holds membership with the Children's Hospital Association (CHA). These organizations along with countless others have been working tirelessly to support the Accelerating Kids' Access to Care Act.

While Medicaid covers about one half of all children nationally, only about one third of the children cared for by the University of Iowa are covered by Medicaid<sup>1</sup>. So, we are truly taking care of the most vulnerable part of our population, children in poverty. Investing in children's health is not just the right thing to do. It also pays off in the long-term, as we know that children who receive these services through Medicaid have better health as adults<sup>2-4</sup>.

The University of Iowa Stead Family Children's Hospital is the only academic, university associated children's hospital in the state of Iowa. At The University of Iowa, we have over 200 doctors who are **solely** dedicated to the care of children. In many cases, our University of Iowa pediatric care doctors are the **only** specialists of their kind in the state and often the surrounding region. And for children with rare diseases and complex medical conditions, our University of Iowa pediatric doctors are usually the only doctors with any experience with those rare diseases. Because of this, we sometimes have children with rare diseases for whom we are the only place in the state, region, and even the whole country with the knowledge to treat them—and we do so with high quality and innovative care designed for children and their families to continue to thrive. For children outside of Iowa, we may also be the closest medical center with expertise in rare pediatric diseases.

The bipartisan Accelerating Kids' Access to Care Act would improve children's access to necessary out-of-state health care by streamlining the burdensome and time-consuming Medicaid provider screening and enrollment process.

Children on Medicaid often must travel to different states to receive care when the services they need are not available in their own state. This is particularly true for children with medically complex conditions, like cancer or other rare diseases, who must regularly access highly specialized providers found in children's hospitals, which are often treating children from many different states at any given time.

Today, children on Medicaid needing care outside their home states often experience delays because some state Medicaid programs require out-of-state providers to be screened and enrolled into their program even if the provider is already enrolled and in good standing with their home state Medicaid program or Medicare. This process of enrolling in multiple Medicaid programs consumes valuable time and resources, increases program costs, and most importantly delays children's access to care.

As an example, Dr. Polly Ferguson, our division director of Rheumatology, is the world's expert for a rare, and possibly fatal inflammatory bone condition called chronic recurrent multifocal osteomyelitis or CRMO. Children with this disease can have bone inflammation that is painful, deforming, and they can even die from this disease. Most doctors never even see a single case of this rare disease, and if they do, because it is so rare, they might miss the diagnosis. But Dr. Ferguson's work has helped uncover life-saving treatment for this rare disease<sup>5</sup>. Because of her expertise, patients come to see Dr. Ferguson from all over the state of Iowa, all 50 states and even internationally. But if the child with this condition is insured by an out-of-state Medicaid program evaluation and treatment by Dr. Ferguson could, depending on the state, require multiple levels of administrative approval, could be denied administratively, and could be delayed because of other administrative burdens. These delays of weeks to months could potentially cause irrevocable harm to the child's health and future. Sadly, we know of children with this rare disease who have already suffered the consequences of this administrative red tape when they could have been helped very quickly by Dr. Ferguson.

Another area where the University of Iowa Stead Family Children's hospital has unique expertise is for children with intractable epilepsy. We are the only comprehensive pediatric epilepsy program in the state, with expert pediatric neurosurgeons and pediatric epilepsy doctors, and state of the art pre-surgical and surgical equipment. For example, our University of Iowa's division director for Pediatric Neurology, Dr Aaron Boes, runs the only local transcranial magnetic stimulation Center for Excellence<sup>4</sup>, where he can use a very powerful magnet to briefly turn parts of the brain off in order to determine if they are suitable areas for surgical resection. Delays in approval to be seen by Dr. Boes and his team for children from out-of-state Medicaid can (and has) meant children having to live with more seizures for a longer time, and causes suffering for these patients and their families.

I have given you a few examples where children with rare diseases and complex medical needs from outside of Iowa could be helped by the bill under discussion, but the reciprocal is also of course true: there will be cases where children on Iowa Medicaid with rare diseases and

complex medical needs might be greatly helped by receiving their care in an expedited fashion in another state. This bill is good for Iowa's children, and good for children across the country.

**The Accelerating Kids' Access to Care Act would:**

- Create a new pathway for pediatric providers to enroll in multiple state Medicaid programs if certain requirements are met, including that they are in the lowest category for potential program integrity issues and are enrolled in their home state Medicaid program.
- Only focuses on the screening and enrollment of providers and not on authorization of care by an out-of-state provider nor payment rates for any such care, leaving both issues within the purview of state Medicaid agencies.

I urge this Committee to act now and pass H.R. 4758, Accelerating Kids Access to Care Act.

Thank you for the opportunity to testify before you today.

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<sup>1</sup> <https://www.census.gov/library/stories/2022/09/uninsured-rate-of-children-declines.html>,

<sup>2</sup> Boudreaux MH, Golberstein E, McAlpine DD. The long-term impacts of Medicaid exposure in early childhood: Evidence from the program's origin. *J Health Econ*. 2016 Jan;45:161-75. doi: 10.1016/j.jhealeco.2015.11.001. Epub 2015 Nov 19. PMID: 26763123; PMCID: PMC4785872, [https://www.mitpressjournals.org/doi/abs/10.1162/REST\\_a\\_00677](https://www.mitpressjournals.org/doi/abs/10.1162/REST_a_00677).

<sup>3</sup> Sarah R. Cohodes & Daniel S. Grossman & Samuel A. Kleiner & Michael F. Lovenheim, 2016. "[The Effect of Child Health Insurance Access on Schooling: Evidence from Public Insurance Expansions](#)," *Journal of Human Resources*, University of Wisconsin Press, vol. 51(3), pages 727-759., <https://ideas.repec.org/a/uwp/jhriss/v51y2016i3p727-759.html>.

<sup>4</sup> Brown DW, Kowalski AE, Lurie IZ. Long-Term Impacts of Childhood Medicaid Expansions on Outcomes in Adulthood. *Rev Econ Stud*. 2020 Mar;87(2):792-821. doi: 10.1093/restud/rdz039. Epub 2019 Jul 25. PMID: 32863441; PMCID: PMC7453338., <https://academic.oup.com/restud/article/87/2/792/5538992>.)

<sup>5</sup> Aksentijevich I, Masters SL, Ferguson PJ, Dancey P, Frenkel J, van Royen-Kerkhoff A, Laxer R, Tedgård U, Cowen EW, Pham TH, Booty M, Estes JD, Sandler NG, Plass N, Stone DL, Turner ML, Hill S, Butman JA, Schneider R, Babyn P, El-Shanti HI, Pope E, Barron K, Bing X, Laurence A, Lee CC, Chapelle D, Clarke GI, Ohson K, Nicholson M, Gadina M, Yang B, Korman BD, Gregersen PK,

van Hagen PM, Hak AE, Huizing M, Rahman P, Douek DC, Remmers EF, Kastner DL, Goldbach-Mansky R. [An autoinflammatory disease with deficiency of the interleukin-1-receptor antagonist](#). *N Engl J Med*. 2009 Jun 4;360(23):2426-37. doi: 10.1056/NEJMoa0807865. PMID: 19494218; PMCID: PMC2876877.

<sup>6</sup> <https://uihc.org/services/transcranial-magnetic-stimulation-tms>

Summary: Dr. Alex Bassuk Testimony Before the Committee on Energy and Commerce, Subcommittee on Health, “Legislative Proposals to Support Patients with Rare Diseases”, February 29<sup>th</sup>, 2024

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I urge this Committee to act now and pass H.R. 4758, Accelerating Kids Access to care Act. Thank you for the opportunity to testify before you today.

<sup>1-4</sup> Please see full testimony for references.