Background: Care delivered in the home and community-based setting (HCBS) is a critical place of treatment for many children with medical complexity (CMC) and other developmental disabilities. CMC have multiple transitions between hospital and home and rely on HCBS to keep them out of the hospital or institutional-based settings. Many states cover HCBS through 1915(c) Medicaid waivers that allow states to waive certain Medicaid income eligibility criteria and define high-risk populations based on age, medical condition(s) and disability status instead. All waiver programs must cost the federal government no more than if the states did not have the waiver (i.e., cost-neutrality) which often means enrollment limits, waiting lists, or individual cost limits that can result in gaps in care. We sought to evaluate how states are covering medically complex children through 1915(c) waivers.

Methods: Data elements were extracted from Medicaid 1915(c) approved waiver applications for all included waivers targeting any pediatric age range through October 31, 2018. We developed an aggregate overall coverage score calculated for each waiver. See the following for more detail:
https://www.researchprotocols.org/2019/7/e13062/

Results: 142 waivers across 45 states were included in this analysis. Even though there was uniformity in the Medicaid applications, there was great heterogeneity in how waiver eligibility, transition plans, services covered, and wait lists were defined. Only 1 state (New York) has a waiver for each of the defined target groups. The most common waiver types include those targeting autism/ID/DD (60.6%) followed by disabled sub-groups including medical fragility, technology dependence, HIV/AIDS, brain injury (24.6%), disabled (physical) (9.9%) and mental illness/serious emotional disturbance (4.9%) (see Figure 1). A total of 91 waivers (64.7%) include both child and adult age ranges in the waiver eligibility. Specific services that waivers covered varied widely with 81% of waivers covering respite care and only 7.7% of waivers covering any form of education services offered to family or school about care of the child. The mean dollars spent per person per year were also highest for autism/ID/DD waivers (see Figure 2).

Conclusions: We recommend greater links between public policy, infrastructure, health care providers, and a family-centered approach to extend this research. Specifically, we recommend that age eligibility for waivers be limited to children and not a combination of children and adults. Additionally, these waivers should incorporate transition to adult-based
waivers as a part of the transition plan. Finally, there are CMC sub-groups (serious emotional disturbance/mental illness) that are disproportionately under-funded through waivers.

Figure 1: 1915(c) waivers by target group n = 142 across 45 states

Figure 2: Mean dollar per person per year by waiver target group
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