



State Adoption of Medicaid 1915(c) Waivers for Children and Youth with Autism Spectrum Disorder

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About the Issue

Since Congress passed legislation in 1981 giving the Department of Health and Human Services the authority to grant states Medicaid 1915(c) home and community-based service waivers for individuals with disabilities, most states have adopted one or more 1915(c) waivers for individuals with intellectual and developmental disabilities. However, few states have adopted a 1915(c) waiver specific to children and youth with Autism Spectrum Disorder (ASD).

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Background

The rate of children diagnosed with ASD in the U.S. increased approximately 78 percent between years 2002 and 2008 (CDC, 2012). The Centers for Disease Control and Prevention (CDC) estimates that 1 in 68 youth have an ASD diagnosis (CDC, 2014, b). ASD is more prevalent in boys than in girls, and children who are White are more likely to be identified as having ASD than children who are Black or children who are Hispanic (CDC, 2014, a).

ASD is a condition characterized by challenges related to social interactions, communication, and behavior (American Psychiatric Association [APA], 2014). ASD is considered a "spectrum" disorder because individuals share common symptoms, but the combination of symptoms and severity of the condition may vary by individual (APA, 2014).

Medicaid funds approximately 40 percent of long-term services and supports, including home and community-based services in the U.S. (Kaiser Commission on Medicaid and the Uninsured [KCMU], 2013).

State Medicaid programs may opt to provide home and community-based services to children, transition age youth, and adults with ASD through different mechanisms. Among state options are a 1915(c) waiver, a 1915(i) state plan option, the mandatory home health benefit, and the optional personal care benefit (KCMU, 2012). Of these, 1915(c) waivers are the most prevalent mechanism states utilize to provide home and community-based services to individuals with disabilities (KCMU, 2012).

With Medicaid 1915(c) waivers, states may offer home and community-based services to individuals with disabilities who would otherwise receive care in an institution. Such waivers also allow states to waive certain financial and diagnosis-related Medicaid eligibility criteria to qualify individuals for Medicaid services. Additionally, 1915(c) waivers let states elect groups of individuals with disabilities to serve through a waiver, establish waiver enrollment caps, and determine services offered under a waiver (Medicaid.gov, n.d., a).

A 9-state study conducted by Abt Associates Inc. related to state Medicaid provisions for children (ages 0 through 13), transition age youth (ages 14-21) and adults with ASD reported that states perceived that their Medicaid program would need to offer ASD-specific programs in order to meet the increasing demand for services (Mauch, Pfefferle, Booker, Pustell, & Levin, 2011).

With the exception of Arizona, Vermont, and Rhode Island,¹ all states offer a 1915(c) waiver for individuals with intellectual and/or developmental disabilities (Medicaid.gov, n.d., b). In 2014, 11 states had adopted and implemented a 1915(c) waiver specific to children and youth with ASD. Indiana and Nebraska also adopted 1915(c) waivers for these individuals but terminated their waivers, Indiana in 2012 and Nebraska in 2014 (Medicaid.gov, n.d., b).

Methods

Given Medicaid's role as the largest funding source for services and supports for children and youth with ASD in the U.S. and the limited uptake of a 1915(c) waiver for this population relative to populations of individuals with other disabilities, this research sought to examine facilitators and barriers that states encountered in their pursuit to adopt this waiver.

Quantitative methods were used to accomplish this aim. A link to an electronic survey was emailed to Medicaid Directors of 49 states and the District of Columbia. (Arizona

¹ Arizona operated its Medicaid program under an 1115 demonstration waiver beginning in 1982. Rhode Island adopted a global 1115 demonstration waiver in 2009 that includes a healthcare eligibility category for children with disabilities and special needs, and Vermont adopted a statewide 1115 demonstration waiver in 2005.

was not contacted as Arizona has operated its Medicaid program through an 1115 demonstration waiver since program inception). Up to two follow-up emails were sent to states that did not respond. For non-responding states, a Medicaid long-term care official or another official in a department with responsibility for providing services to children and youth with ASD was emailed the aforementioned invitation to participate. A maximum of three follow-up telephone call attempts were made to the second contact if a survey submission was not received.

Several steps were taken to ensure the integrity of the survey data. The survey utilized Snap Survey software, a professional survey and analysis tool (Snap Survey, 2014). Survey respondents were assured of the confidentiality of their responses. And, response data were stored using password protected Snap software, which were accessible to only the researchers and were monitored by the grant project manager. Stata statistical software was utilized for descriptive analyses.

The survey contained two parts. The first section inquired about perceptions of factors that positively affected state adoption of a 1915(c) waiver for children and youth with ASD, as well as perceived barriers to the adoption of this waiver. The second section examined services that states provide to children and youth with ASD and through what provision(s) they each provide.

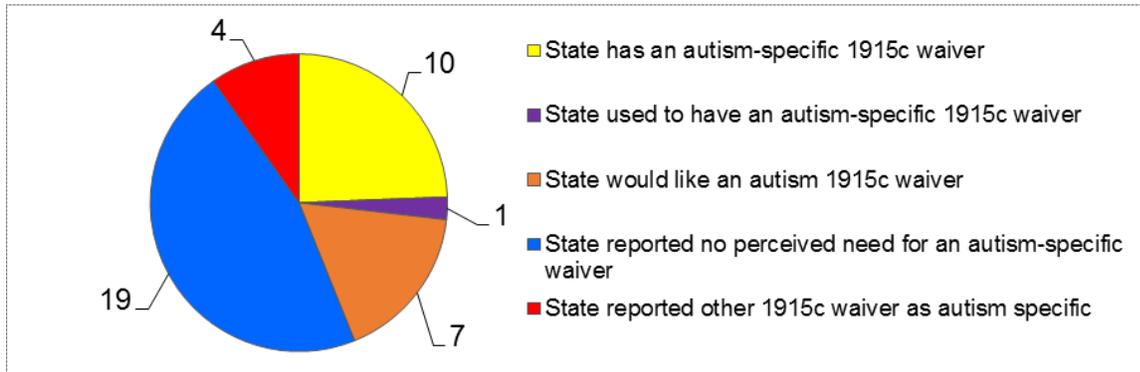
The survey utilized the general model of state policy adoption put forth in Miller's *Synthesis of State Health Policy Making Determinants, Theories, and Methods* (2005). Survey content was developed from the findings of a qualitative pilot study in 5 states that had adopted a Medicaid 1915(c) waiver specific to children and youth with ASD (Merryman, Herr, Kelly, Phelps, Robertson, Rose, et al., 2013).

Findings

An 84 percent survey response rate was attained. Responses were received from 41 states and the District of Columbia. Louisiana reported unique circumstances related to its provision of services for children and youth with ASD and was excluded from this analysis.

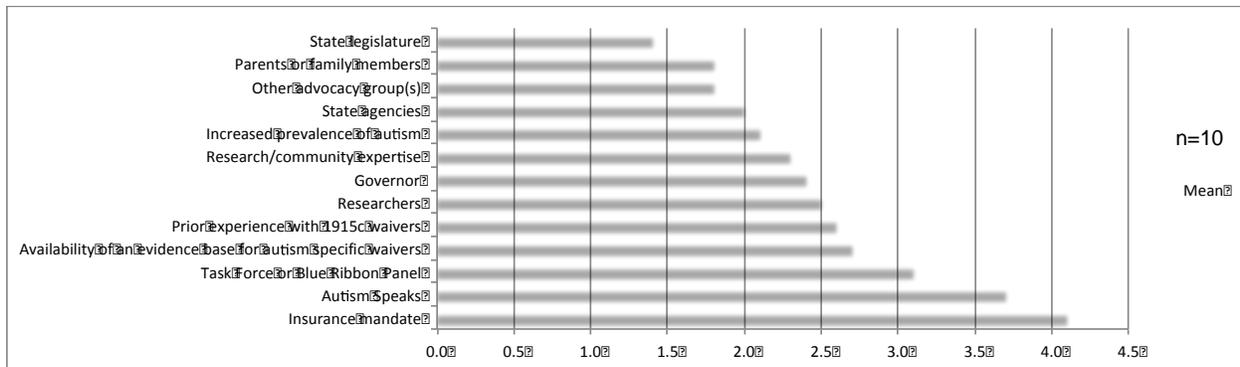
Among the remaining 40 states and the District of Columbia, 18 states and the District of Columbia reported no perceived need for a 1915(c) waiver specific to children and youth with ASD, ten states indicated they offer a 1915(c) waiver specific to children and youth with ASD, seven states reported they would like this waiver, four states reported another 1915(c) waiver as autism-specific, and one state indicated it used to have a Medicaid 1915(c) waiver specific to this population (see Figure 1).

Figure 1. Status of State Adoption of an Autism-Specific Medicaid 1915(c) Waiver



States that adopted this waiver were asked to, “Please indicate how influential the following factors were in your state’s adoption of a 1915(c) waiver for children and youth with autism.” A 5-point Likert scale with 1 representing “Extremely” and 5 representing “Not at all” was utilized. Perceived state legislature support, support from parents or family members, and advocacy group support were ranked as most important among these states. In this subgroup, the existence of an autism private insurance mandate in a state was perceived to be the least influential facilitator in the adoption of this waiver (see Figure 2).

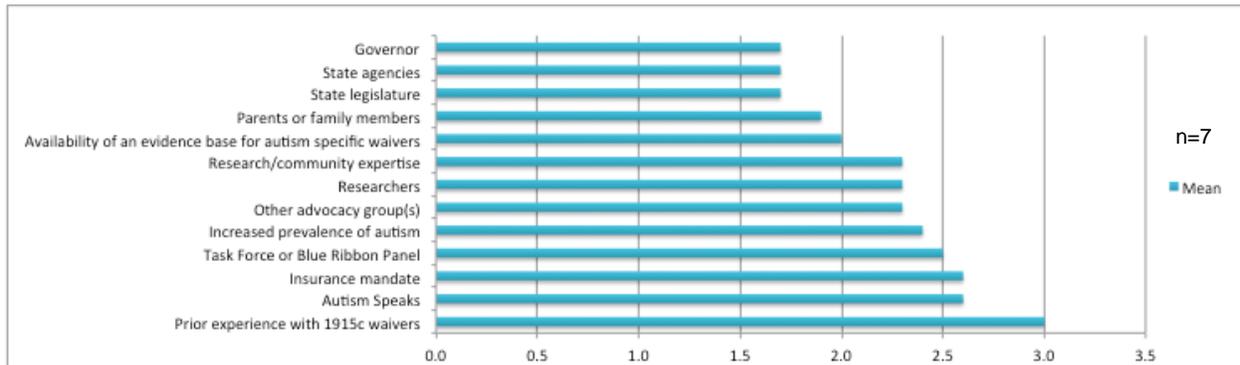
Figure 2. Perceived Facilitators in State Adoption of an Autism-Specific Medicaid 1915(c) Waiver for Children and Youth by States That Adopted This Waiver



States that would like to adopt a 1915(c) waiver specific to children and youth with ASD were asked to, “Please indicate how influential the following would be in your state’s pursuit of adoption of a 1915(c) waiver for children and youth with autism?” The aforementioned 5-point Likert scale was utilized. Perceived state legislature support, state agency support, and support from the Governor were reported as the most and equally influential factors in these states’ efforts to adopt a 1915(c) waiver. And, among

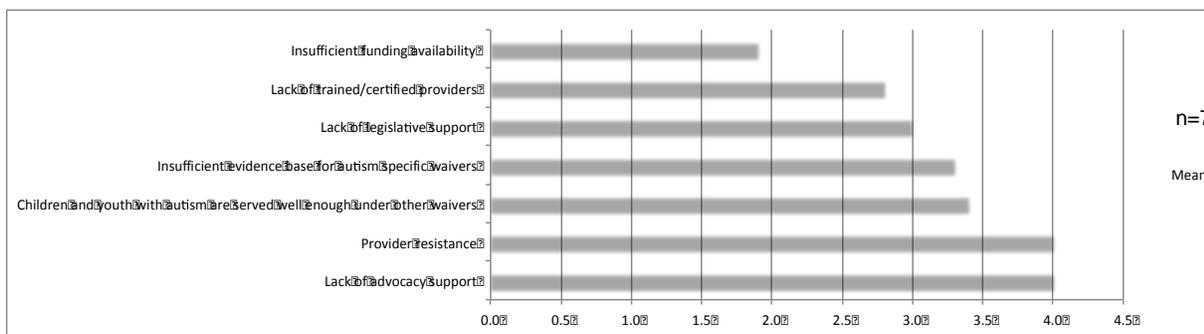
this subset, prior experience with 1915(c) waivers was perceived as the least influential factor in the adoption of a waiver (see Figure 3).

Figure 3. Perceived Facilitators in State Adoption of an Autism-Specific Medicaid 1915(c) Waiver for Children and Youth by States That Would Like to Adopt This Waiver



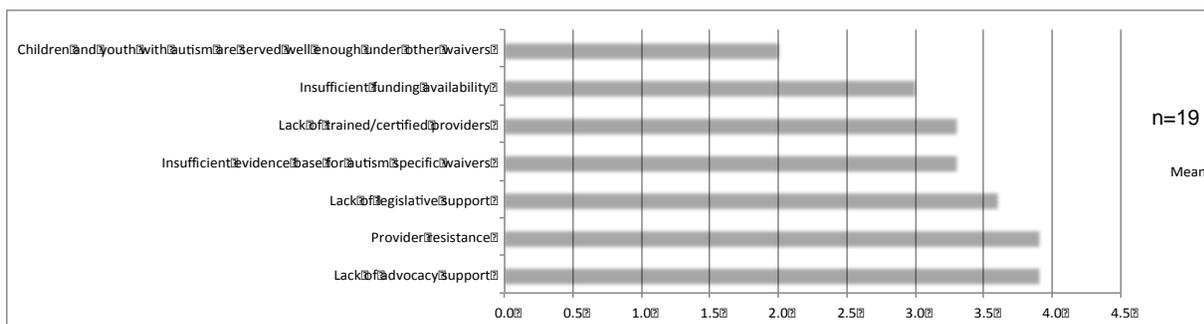
States that would like to adopt a 1915(c) waiver specific to children and youth with ASD were asked, “How much do the following factors explain why your state has not adopted a Medicaid 1915(c) waiver for children and youth with autism?” A 4-point Likert scale with 1 representing “Completely” and 4 representing “Not at all” was utilized. Insufficient funding availability was perceived as the most influential barrier to adoption of a 1915(c) waiver among this subset of states. Perceived lack of trained/certified providers, and a lack of legislative support were reported as the second and third most influential barrier to adoption of this waiver, respectively (see Figure 4).

Figure 4. Perceived Barriers to State Adoption of an Autism-Specific Medicaid 1915(c) Waiver for Children and Youth by States That Would Like This Waiver



Results from states that chose not to adopt this waiver indicate that state officials perceived that children and youth with ASD are served well enough under other waivers and insufficient funding availability as the most influential barriers to waiver adoption, respectively. A perceived lack of advocacy support was reportedly the least influential obstacle to waiver adoption among this subset of states (see Figure 5).

Figure 5. Perceived Barriers to State Adoption of an Autism-Specific Medicaid 1915(c) Waiver for Children and Youth by States with No Perceived Need for This Waiver



Most states used a broader 1915(c) waiver targeted toward individuals with intellectual and developmental disabilities to provide Medicaid services to children and youth with ASD. The broader 1915(c) waiver was used by 25 states to provide services to children and 27 states to provide services to youth with ASD. States often used the broader 1915(c) waiver in combination with an autism-specific 1915(c) waiver, a 1915(c) waiver specific to children, and/or another 1915(c) waiver, most often for children with serious emotional disturbance.

Discussion

Among states that adopted a 1915(c) waiver specific to children and youth with ASD and states that would like to adopt this waiver, political support was perceived as either the most influential or one of the most influential factors in their waiver adoption process. This finding aligns with previous research that demonstrated political support to be a facilitator in the adoption of 1915(c) waivers (Miller, Elder, Kitchener, Kang & Harrington, 2008) as well as influential in states' broader efforts to rebalance their long-term care systems away from institutional care (Harrington, Carrillo, Wellin, Miller, & LeBlanc, 2000; Miller, Kirk, & Shockley, 2014). Based on these findings, states that would like to adopt an autism-specific 1915(c) waiver may find it useful to discuss strategies used to obtain political support for the waiver with states that have successfully adopted an autism-specific waiver.

Among states that would like to adopt an autism-specific 1915(c) waiver as well as those with no perceived need for this waiver, insufficient funding availability was perceived as the most influential or second most influential barrier to adoption. Research has demonstrated that home and community-based services are less costly than institutional care (Kitchener, Ng, Miller & Harrington, 2006) and may be associated with lower total long-term care spending (Kaye, LaPlante, & Harrington, 2009; Miller, 2010). Thus, disseminating evidence that addresses cost concerns may facilitate expansion.

One explanation for the lack of funding availability for home and community-based services among states is discussed in a report commissioned by U.S. Senator Tom Harkin, former Chairman of the Committee on Health, Education, Labor, and Pensions

(HELP) Committee (2013). The report found that most states view provision of home and community-based services from a budgetary and welfare perspective rather than a civil rights perspective inherent in the Americans with Disabilities Act (1990) and the U.S. Supreme Court decision in *Olmstead vs. LC.* (1999). The *Olmstead* decision held that providing care in institutions for individuals with disabilities who could live in the community with services and supports is a violation of their civil rights (United States Senate: Health, Education, Labor and Pensions Committee, 2013). Given states' perceptions of funding as a barrier to adoption of this waiver, coupled with findings from Senator Harkin's report, advocacy for adoption of a Medicaid 1915(c) waiver specific to children and youth with ASD from a civil rights perspective may facilitate further adoption of this waiver.

Most states use a 1915(c) waiver for individuals with intellectual and developmental disabilities to provide Medicaid services to children and youth with ASD. While some states perceived autism-specific 1915(c) waivers to be beneficial in designing services for children and youth with ASD, other states perceived their service needs to be sufficiently met through other waivers and Medicaid state plan benefits (e.g., the optional rehabilitation benefit). There is some evidence that provision of services to children and youth with ASD through an autism-specific 1915(c) waiver is associated with improvement in independent living skills and family quality of life, relative to children and youth with ASD on a registry list (Eskow, Chasson & Summers, 2014). A next step would be to evaluate whether states' use of an autism-specific 1915(c) waiver is associated with enhanced access and outcomes, relative to state use of other Medicaid service approaches.

This research is not without limitations. Survey respondents were asked to provide their perceptions; a next step would be to examine these perceptions in a multivariate analysis of state adoption (Miller, et al., 2008). Additionally, despite an 84 percent survey response rate, there may have been a difference in perceptions between individuals from states that completed the survey and those from states that are unaccounted for due to not completing the survey. Lastly, interviews were initially sought with state Medicaid Directors, however in some states other state officials with knowledge of Medicaid home and community-based services specific to this population responded to this survey. Hence, different levels of expertise on the subject of this study may exist among respondents.

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