

Research

Electronic Video Monitoring in Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities



www.c-q-l.org

Electronic Video Monitoring in Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities

Carli Friedman & Mary C. Rizzolo

Corresponding Author:

Carli Friedman, PhD
CQL | The Council on Quality and Leadership
100 West Road, Suite 300
Towson, MD 21204
cfriedman@thecouncil.org

Mary C Rizzolo, PhD, CQL | The Council on Quality and Leadership

Acknowledgments:

This paper was sponsored in part by a grant from the Administration on Intellectual and Developmental Disabilities (90DN0296).

Reference:

Friedman, C. & Rizzolo, M. C. (2017). Electronic video monitoring in Medicaid Home and Community Based Services Waivers for people with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 14(4), 279–284.
<https://doi.org/10.1111/jppi.12222>

Abstract

Background

While the number of available caregivers for people with intellectual and developmental disabilities (IDD) is reducing, the number of people who need care and support is steadily increasing, effectively creating a vacuum of care. In response to this increasing problem, and as a result of advances in technology, telecare and remote monitoring in the long-term support of people who are aging or have IDD are becoming more prominent. Despite noted benefits, telecare and other forms of technological surveillance are relatively new for people with intellectual and developmental disabilities. Medicaid Home and Community Based Services (HCBS) Section 1915(c) waivers are a critical funding stream for people with IDD's long-term support needs in the United States.

Specific Aims

In order to examine the implementation of electronic monitoring technology for people with IDD, we examined which HCBS waivers were providing electronic monitoring services and how they were doing so.

Method

Ninety-nine IDD related HCBS 1915(c) waivers (44 states and the District of Columbia) were collected for fiscal year 2013 from the United States CMS Medicaid.gov website. We then examined this data to determine, if applicable, the electronic monitoring services provided, the projected number of users, and the average cost of each unit of service. We also examined the electronic monitoring service definitions to determine themes across services.

Findings

We found seven out of the 99 HCBS FY 2013 waivers (7.1%) provided electronic monitoring services through nine different services. Moreover, very little funding was allocated for these services.

Discussion

Our findings highlight that electronic monitoring services are largely not being utilized for the more than 600,000 people with IDD on Medicaid HCBS waivers. As HCBS waivers look to reduce costs and continue to support people with IDD we believe more states will consider these technologies.

Electronic Video Monitoring in Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities

The U.S. Department of Health and Human Services (2006) estimates 1.2 million direct support professionals (DSPs) will be needed to support people with intellectual and developmental disabilities (IDD) by 2020, yet as of 2007 there were only 625,000 DSPs supporting people with IDD (Hewitt & Larson, 2007). While the number of available caregivers for people with IDD is reducing, the number of people who need care and support is steadily increasing, effectively creating a vacuum of care (Brewer et al., 2010, Niemeijer et al., 2010). In response to this increasing problem, and as a result of advances in technology, telecare and remote monitoring in the long-term support of people who are aging or have IDD are becoming more prominent (Brewer et al., 2010, Perry et al., 2009). These new technologies aim to save costs, reduce staff burden, assist with activities of daily living while allowing independence, and monitor for safety and harm (Brewer et al., 2010, Niemeijer et al., 2010). As such, this technology aims to be both preventative as well as responsive (Perry et al., 2009, Niemeijer et al., 2010). Devices such as Digital Enhanced Cordless Telecommunications (DECT) phones, movement sensors, acoustic surveillance, electronic bracelets, and GPS tags have been used to measure physical patient conditions and serve as outpatient telehealth clinics (Niemeijer et al., 2014, Spaulding et al., 2012, Szeftel et al., 2012, Welsh et al., 2003).

A more specific type of telecare technology is video surveillance. Brewer et al. (2010) discusses the use of this remote monitoring technology in depth:

a broadband connection to the Internet using either cable or a digital subscriber line (DSL), a camera with pan, tilt, zoom capabilities, voice over IP (VOIP) communications between the client and the remote care provider...and motion detection sensors. The motion sensors were used to alert remote caregivers when there was activity in the residence that might need their direct attention. If the

sensors detected movement, the remote caregiver's computer display would change the screen image from small to full screen. (p. 266)

This type of video surveillance is seen as an alternative to more restrictive placements which would include physical restraints and/or locked doors because it can help prevent falls and other harmful incidents (Boekhorst et al., 2013, Niemeijer et al., 2010, Welsh et al., 2003). In addition to these benefits for residents, it can also help streamline caregiver roles and responsibilities. For example, when Sugihara et al. (2014) used cameras in the common spaces of a group home for the elderly, caregivers there reported it helped with their work as they needed to check up on people less. However, Sugihara et al. (2014) also found that the amount of caregiving time with the cameras did not change; thus, it is possible that this system actually allowed the caregivers to use their time more efficiently by allowing them to just look at the monitors and not requiring physical oversight.

Despite these noted benefits, as evidenced by a shortage of literature, telecare and other forms of technological surveillance are relatively new for people with intellectual and developmental disabilities (Brewer et al., 2010, Niemeijer et al., 2010). Brewer et al. (2010) completed interviews with clients, staff, and managers about the use of telecare systems in their residential setting. They found the majority felt telecare allowed their residents to be more independent, especially because it was believed to be effective for safety and security (Brewer et al., 2010). Niemeijer et al.'s (2014) ethnographic study of residential and nursing home settings for people with IDD and dementia using these types of technologies found surveillance bracelets allowed residents to move around more because they were given more freedom. These residents would even wander and find new 'personal' spaces (Niemeijer et al., 2014). However, at the same time, some residents did not like the surveillance bracelets because they thought it was evidence of their stigmatized position as a patient (Niemeijer et al., 2014). Finally, Buono and

Città (2007) also discuss telecare technology usage with people with IDD. However, their study focused more on conferencing technology with family/caretakers to support caretakers with self-care, problem behaviors, education/skill building of people with IDD, and support and education for families (Buono and Città, 2007).

United States (U.S.) Medicaid funds the majority of long-term supports for people with IDD (Removed for review, 2013). More specifically, Medicaid Home and Community Based Services (HCBS) Section 1915(c) waivers are a critical funding stream for people with IDD's long-term community support needs (Removed for review, 2013). Each year HCBS waivers continue to grow because of both the significant benefits of community living and the deinstitutionalization movement (Lakin et al., 2011, Mansell and Beadle-Brown, 2004). In order to examine the implementation of electronic monitoring technology for people with IDD, we examined which HCBS 1915(c) waivers were providing electronic monitoring services. In doing so, we also examined how many users these waivers were projecting services for as well as how much they were projecting to spend on these services.

Method

Methods for this study were similar to a national study of HCBS Medicaid waivers for people with IDD by Removed for review (2013) and a national study of dental services in HCBS Medicaid waivers for people with IDD by Removed for review (2014). HCBS 1915(c) waiver data relating to either intellectual disability (ID), developmental disability (DD), mental retardation (MR), or autism (ASD) was obtained from the United States CMS Medicaid.gov website over a 12 month period (June 2013 to June 2014). No age limitations were imposed. When we were aware of waivers that were not accessible on the CMS Medicaid.gov website, state developmental disability agencies and division websites were reviewed. It should be noted

that we were aware of six fiscal year (FY) 2013 waiver applications that we were not able to access through either of these methods. For this reason, these waivers were not included in the analysis and this should be considered in our findings.

Ninety-nine IDD related HCBS waivers (44 states and the District of Columbia) were collected for FY 2013 (July 1, 2012 to June 30, 2013). Some states (n=19) used the federal fiscal years of October 1, 2012 to September 30, 2013, while some (n = 15) used the 2013 calendar year. In this study we use the term fiscal year (FY) for consistency. We then examined this data to determine, if applicable, the electronic monitoring services provided¹, the projected number of users, and the average cost of each unit of service. We also examined the electronic monitoring service definitions to determine themes across services.

Findings

Service Definitions

The HCBS services that fell under the umbrella of electronic monitoring included the following titles: “electronic monitoring,” “remote assistance,” “remote monitoring,” “remote monitoring equipment,” and “electronic monitoring/surveillance system and on-site response.” Generally, these services included oversight and monitoring through off-site electronic surveillance such as a “live video feed, live audio feed, motion sensing system, radio frequency identification, web-based monitoring system, or other device approved by the department.” This equipment needed to include a visual indicator so that the person with IDD observed knew when the system was operating. These services also often noted two-way communication was a requirement of these devices.

¹ It should be noted that, although similar, Personal Emergency Response Systems (PERS) services are unique from electronic monitoring and therefore not included in this study.

The purpose of electronic monitoring services was generally to “replace or reduce services,” or “increase a members independence and ensure health and welfare.” Oklahoma’s Community waiver (OK179.R05.00) detailed this purpose in more depth, explaining this service “may be appropriate for member’s [sic] who don’t sleep regularly throughout the night or whose behaviors, while awake, don’t pose a danger to himself/herself or others in the home (e.g., sitting in living room watching TV, or pacing a hall) and he/she is not an elopement risk.” While West Virginia’s MR/Developmental Disability waiver (WV133.R05.01) noted this service must ensure health and welfare “in a cost neutral manner.”

As there are many potential ethical issues, consent was also an important aspect of these services. Often services required that both people with IDD and their guardians (if applicable) be informed of benefits and risks and then sign an informed consent form. WV133.R05.01 even went so far as to require approval by a human rights committee.

[INSERT TABLE 1 ABOUT HERE]

Service Expenditures

We found seven out of the 99 HCBS FY 2013 waivers (7.1%) provided electronic monitoring services through nine different services (see table 1). In FY 2013, these nine services projected a total of 842 users and spending of \$31.8 million dollars. Although this may seem like a significant amount of money, it is a very small fraction (0.1%) of the total FY 2013 waiver spending (\$28.0 billion) analyzed.

[INSERT FIGURE 1 ABOUT HERE]

The average projected cost per person for these services was \$23,583; however, these rates varied widely by service (see figure 1). For example, the average annual projected cost per person in Oklahoma’s Community (OK179.R02.00) and Homeward Bound waivers

(OK399.R02.00) was \$75, while in Louisiana's New Opportunities waiver (LA401.R02.02) it was \$199,311. This large discrepancy in average projected costs per person is due in part to the number of hours provided to participants in a year; while OK179.R02.00 and OK399.R02.00 provided 8 hours per year per participant on average, LA401.R02.02 provided 8,760 hours per year per participant on average. On average these electronic monitoring services provided 3,159 hours of services per participant per year. These differences are vast yet waivers did not detail why they capped the average annual hours per participant as they did. The overall average hourly rate² for electronic monitoring services was \$8.76 (see figure 2).

[INSERT FIGURE 2 ABOUT HERE]

Discussion

Only a small number of HCBS waivers are offering electronic monitoring services for people with IDD. In total, only seven out of 99 FY 2013 waivers provided these services. Not only was this a small proportion of waivers, when compared to other services it was also a very small amount of funding. Our findings highlight that electronic monitoring services are largely not being utilized for the more than 600,000 people with IDD on Medicaid HCBS waivers (Braddock et al., 2015). In addition to the low implementation of electronic monitoring services, there was wide variability among the waivers that provided electronic monitoring services in terms of projected total spending, projected spending per participant, and hourly rates. For example, the hourly rate for electronic monitoring services ranged from \$4.54 for West Virginia WV133.R05.01 waiver to \$13.62 for Louisiana LA401.R02.02 waiver, with an average hourly rate of \$8.76; although there is little data to compare if the average hourly rates we found are sufficient, for comparison Bogenschutz et al. (2014) found direct support professionals (DSPs)

² 'Remote Monitoring Equipment' (Ohio's Level One waiver (OH380.R02.02) and Individual Options waivers' (OH231.R03.04)) are provided monthly instead of hourly. For this reason they were not included in the average hourly rate.

mean hourly wage was \$11.26. Since there is relatively little data on electronic monitoring services in the U.S. comparing Medicaid HCBS electronic monitoring implementation to other countries' utilization of these services would be a useful point of inquiry for future research.

When interpreting our findings it should be noted that this study was limited by our lack of access to some waiver applications. As mentioned in the methods, we were aware of six other FY 2013 waiver applications that were not publicly accessible. The effect these waivers would have is unknown and thus must be considered in our findings but it is likely they would follow the same trends of low utilization.

Although all HCBS waivers specify general safeguards, our examination of electronic monitoring services showed particular attention to navigating ethical dilemmas; from our examination of other types of waiver services (e.g. dental services (Removed for review, 2014), mental/behavioral health services (Removed for review, 2015), transportation services (Removed for review, under review)) this appears fairly unique to electronic monitoring services. In addition to the requirement of informed consent as mentioned above, it was not uncommon for those waivers providing electronic monitoring services to specify other ethical requirements. For example, a number of states required regular assessments to determine if the usage of monitoring still ensured the health and welfare of the person with IDD. While others detailed specific policies and procedures for staff that must be followed for service reimbursement. As waivers look to expand these electronic monitoring services, it is important for them to take into account the potential ethical implications as the existing services do. While some researchers working in the area of telecare and monitoring suggest “technology denies personhood altogether” (Niemeijer et al., 2010, pp. 1135-1136), others remind us of the importance of the balance between the right to autonomy, privacy, and safety (Niemeijer et al., 2014, Zwijsen et al., 2011).

Speaking to the need for clear guidelines, Niemeijer et al. (2011) and Niemeijer et al.(2013) warn this technology is currently being put to use in places without ethical guidelines and/or protocol. In addition to an informed consent procedure, staff need to be trained properly on the use of the technology (Niemeijer et al., 2010, Niemeijer et al., 2013).

This technology can be valuable and beneficial for both people with IDD and those providing their care. Although a number of research studies have been examined the ethics of this type of surveillance (Male et al., 1991, Niemeijer et al., 2011, Niemeijer et al., 2013, Perry and Beyer, 2012, Perry et al., 2009, Zwijsen et al., 2011), less have paid attention to how the people being watched feel about it and how it affects their quality of life (Boekhorst et al., 2013, Niemeijer et al., 2010). For example, Brewer et al. (2010) found, “one telecare client stated, ‘they follow me, I don’t like people watching me.’ Another client offered a possible solution to the negative, distant experience when he stated that he would like to ‘see their faces when they talk’” (p. 267). For this reason, it is important research in this area works to understand both ways to increase people with IDD’s feelings towards this type of technology as well as ways to improve their relationships to it. Future use of this technology should also be person centered and designed around their needs (Niemeijer et al., 2011).

Electronic monitoring services are effective methods to expand community care while at the same time being cost effective. As the literature suggests electronic monitoring services can help redirect care to increase caregiver productivity, which can help defray DSP shortages. Moreover, services such as electronic monitoring that help people with IDD stay in the community are beneficial because of the positive outcomes of community living, and cost effective because they help prevent the large costs associated with institutional placements (Braddock et al., 2015; Kim, Larson, & Lakin, 1999; Larson & Lakin, 1989, 2012). As HCBS

waivers look to reduce costs and continue to support people with IDD we believe more states will consider these technologies. In moving forward it is important to remember that electronic monitoring technology needs to not only be cost effective but also improve care; electronic monitoring technology cannot serve as a substitute for personal care and interaction (Niemeijer et al., 2010, Niemeijer et al., 2013).

References

- Boekhorst, S. t., Depla, M., Francke, A., Twisk, J., Zwijsen, S., & Hertogh, C. (2013). Quality of life of nursing-home residents with dementia subject to surveillance technology versus physical restraints: an explorative study. *International journal of geriatric psychiatry*, 28(4), 356-363.
- Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual and Developmental Disabilities*, 52(5), 317-329.
- Braddock, D., Hemp, R., Rizzolo, M. C., Haffer, L., Tanis, E. S., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession*. Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Brewer, J. L., Taber-Doughty, T., & Kubik, S. (2010). Safety assessment of a home-based telecare system for adults with developmental disabilities in Indiana: a multi-stakeholder perspective. *Journal of telemedicine and telecare*, 16(5), 265-269.
- Buono, S., & Città, S. (2007). Tele-assistance in intellectual disability. *Journal of telemedicine and telecare*, 13(5), 241-245.
- [Removed for review] (2015). Mental/behavioral health services: Medicaid Home and Community Based Services 1915(c) waiver allocation for people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, 53(4), 257-270.
<http://dx.doi.org/10.1352/1934-9556-53.4.257>
- [Removed for review] (*under review*). The state of transportation for people with intellectual and developmental disabilities in Medicaid Home and Community Based Services 1915(c)

waivers.

- [Removed for Review] (2014). Dental services: A nationwide study of Medicaid Home and Community-Based Services (HCBS) waiver service allocation. *Inclusion*, 2(1), 17-36.
- Hewitt, A., & Larson, S. (2007). The direct support workforce in community supports to individuals with developmental disabilities: Issues, implications, and promising practices. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(2), 178-187.
- Kim, S., Larson, S. A. & Lakin, K.C. (1999). *Behavioral outcomes of deinstitutionalization for people with intellectual disabilities: A review of studies conducted between 1980 and 1999* (Policy Research Brief Vol. 10). Minneapolis, MN: University of Minnesota, Institute on Community Integration.
- Larson, S. A., & Lakin, K. C. (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Journal of the Association for Persons With Severe Handicaps*, 14(4), 324-332.
- Larson, S.A., & Lakin, K.C. (2012). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S.- studies from 1977 to 2010. *Research & Practice for Persons with Severe Disabilities*, 37(4), 235-246.
- Male, B., El Komy, A., & Clark, C. (1991). Electronic alert system for mentally handicapped adults incapable of consent—civilised technology or civil rights abuse? *Psychiatric Bulletin*, 15(10), 605-606.
- Niemeijer, A., Frederiks, B., Depla, M., Eefsting, J., & Hertogh, C. (2013). The place of surveillance technology in residential care for people with intellectual disabilities: is there an ideal model of application. *Journal of Intellectual Disability Research*, 57(3), 201-

215.

- Niemeijer, A. R., Depla, M. F., Frederiks, B. J., & Hertogh, C. M. (2014). The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care. *Nursing ethics*, 0969733014533237.
- Niemeijer, A. R., Frederiks, B. J., Depla, M. F., Legemaate, J., Eefsting, J. A., & Hertogh, C. M. (2011). The ideal application of surveillance technology in residential care for people with dementia. *Journal of Medical Ethics*, jme. 2010.040774.
- Niemeijer, A. R., Frederiks, B. J., Riphagen, I. I., Legemaate, J., Eefsting, J. A., & Hertogh, C. M. (2010). Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature. *International Psychogeriatrics*, 22(07), 1129-1142.
- Perry, J., & Beyer, S. (2012). Ethical issues around telecare: the views of people with intellectual disabilities and people with dementia. *Journal of Assistive Technologies*, 6(1), 71-75.
- Perry, J., Beyer, S., & Holm, S. (2009). Assistive technology, telecare and people with intellectual disabilities: ethical considerations. *Journal of Medical Ethics*, 35(2), 81-86.
- [Removed for Review] (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1), 1-21.
doi: 10.1352/1934-9556-51.01.001
- Spaulding, R., Velasquez, S. E., He, J., & Alloway, G. A. (2012). Hospital and emergency department resource usage: a cost analysis from a home telehealth project in Kansas. *Journal of telemedicine and telecare*, 18(7), 423-424.
- Sugihara, T., Fujinami, T., Jones, R., Kadowaki, K., & Ando, M. (2014). Enhancing care homes with assistive video technology for distributed caregiving. *AI & SOCIETY*, 1-10.

- Szeftel, R., Federico, C., Hakak, R., Szeftel, Z., & Jacobson, M. (2012). Improved access to mental health evaluation for patients with developmental disabilities using telepsychiatry. *Journal of telemedicine and telecare, 18*(6), 317-321.
- US Department of Health and Human Services. (2006). The supply of direct support professionals serving individuals with intellectual disabilities and other developmental disabilities: Report to Congress. *Washington, DC: Office of the Assistant Secretary for Planning and Evaluation.*
- Welsh, S., Hassiotis, A., O'mahoney, G., & Deahl, M. (2003). Big brother is watching you--the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Aging & mental health, 7*(5), 372-375.
- Zwijnsen, S. A., Niemeijer, A. R., & Hertogh, C. M. (2011). Ethics of using assistive technology in the care for community-dwelling elderly people: An overview of the literature. *Aging & mental health, 15*(4), 419-427.

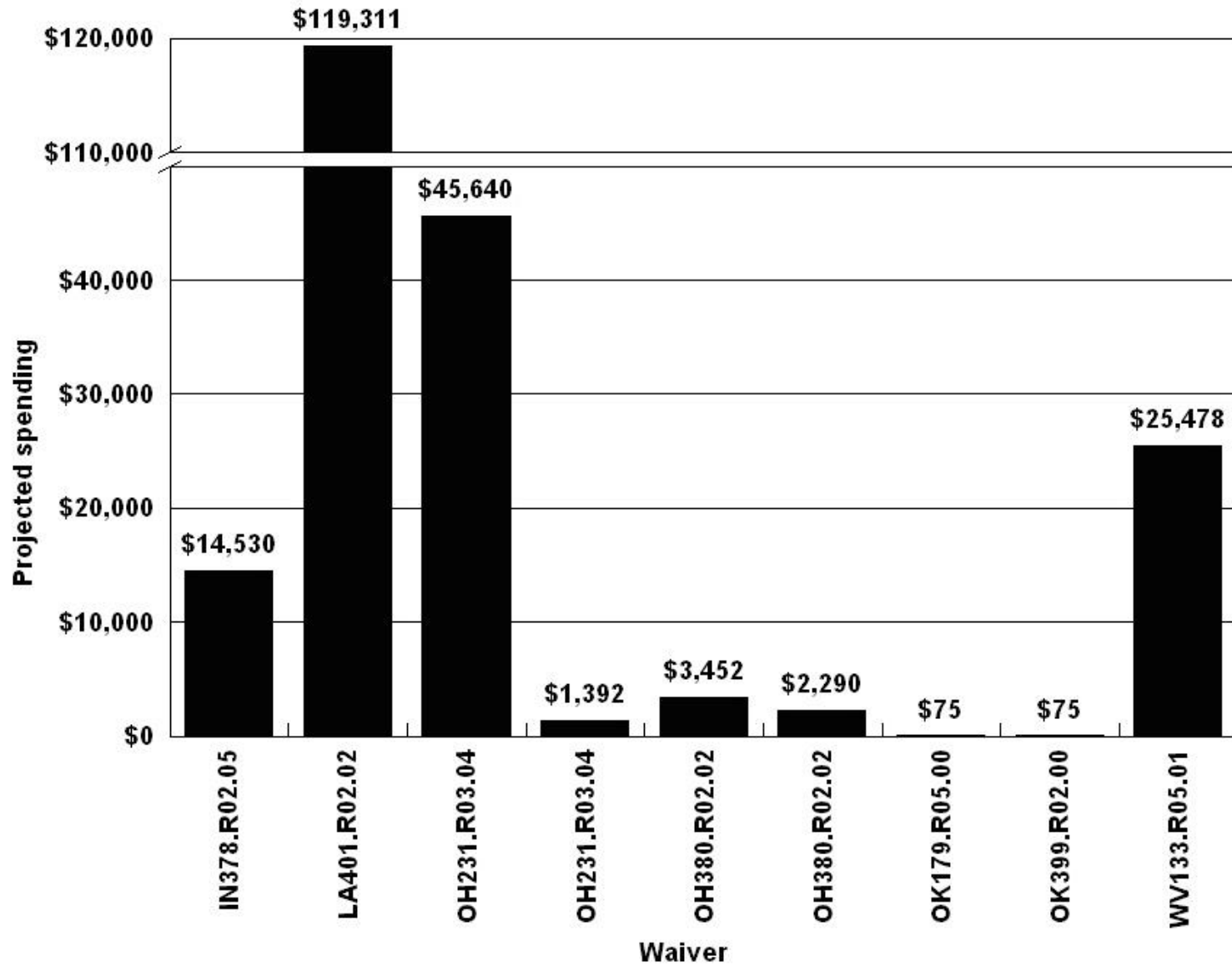


Figure 1. Average projected spending per person on electronic monitoring services in FY 2013.

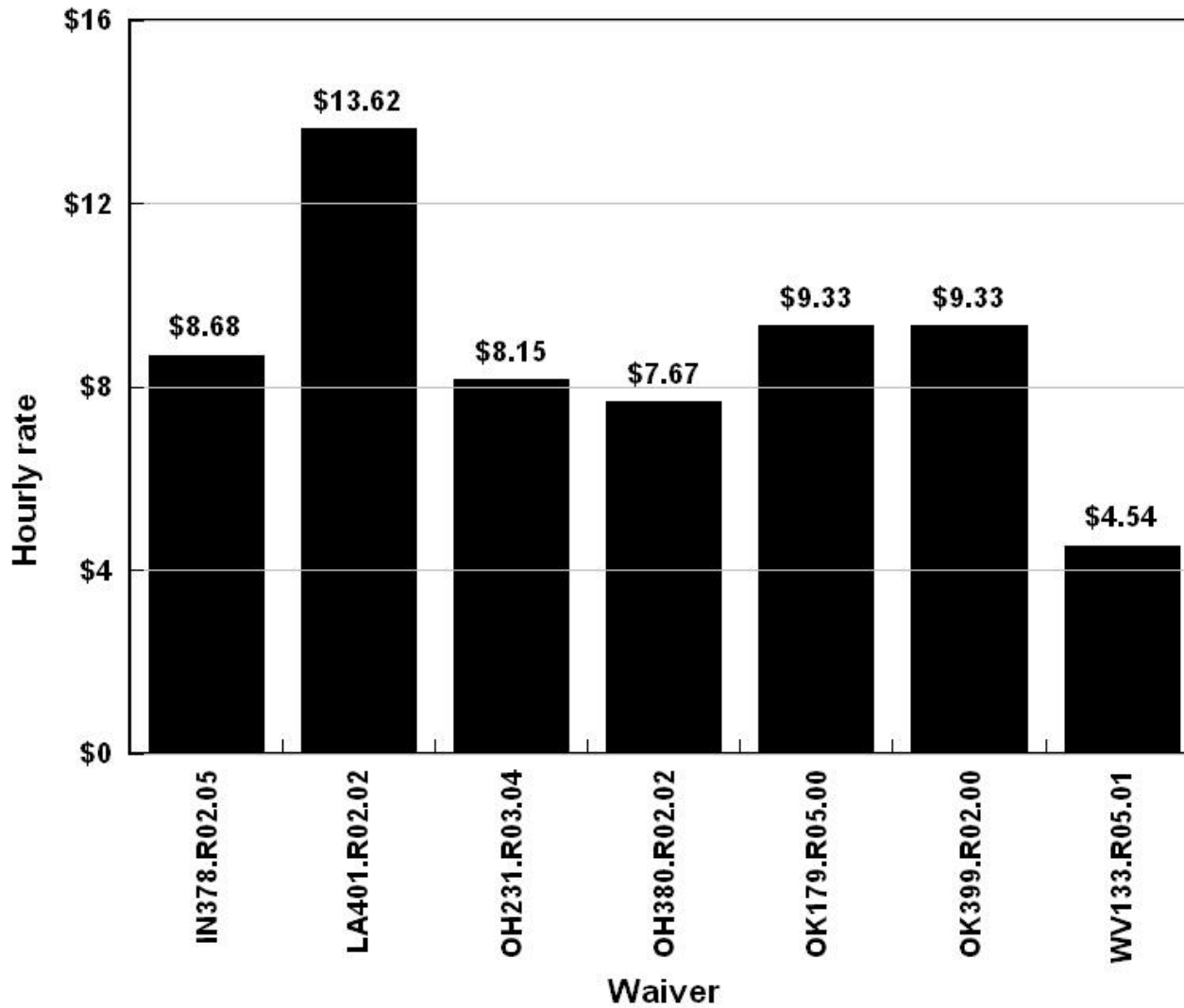


Figure 2. Projected hourly rate per electronic monitoring service. OH231.R03.04 and OH380.R02.00's 'remote monitoring equipment' is not included because it is provided monthly.

Table 1

Electronic monitoring services in fiscal year 2013

| State | Waiver number | Service | Unit | # Users | Component Cost |
|---------------|---------------|---|--------|---------|-----------------|
| Indiana | IN378.R02.05 | Electronic Monitoring | hour | 105 | \$1,525,683.60 |
| Louisiana | LA401.R02.02 | Remote Assistance | hourly | 159 | \$18,970,480.80 |
| Ohio | OH231.R03.04 | Remote Monitoring | hour | 197 | \$8,991,080.00 |
| Ohio | OH231.R03.04 | Remote Monitoring Equipment | month | 197 | \$274,224.00 |
| Ohio | OH380.R02.02 | Remote Monitoring | hour | 14 | \$48,321.00 |
| Ohio | OH380.R02.02 | Remote Monitoring Equipment | month | 14 | \$32,060.00 |
| Oklahoma | OK179.R05.00 | Remote Monitoring | 1 hour | 53 | \$3,955.92 |
| Oklahoma | OK399.R02.00 | Remote Monitoring | 1 hour | 25 | \$1,866.00 |
| West Virginia | WV133.R05.01 | Electronic Monitoring/ Surveillance System and On-Site Response | hour | 78 | \$1,987,321.44 |