

Written Testimony to the Assembly Human Services Committee
Thursday, December 10, 2020 at 3:15 pm
Bill A4013 (Billy Cray's Law)

Thank you Chairwoman Downey and members of the committee for the opportunity to comment in writing regarding bill A4013, Billy Cray's Law, which requires groups homes to install electronic monitoring devices in common areas upon request and uniform consent and permits consensual use of devices in private rooms. For the reasons specified below, Disability Rights New Jersey opposes this bill.

Disability Rights New Jersey is the federally funded, designated protection and advocacy system for people with disabilities in the State of New Jersey. Under our federal enabling statutes, we provide legal representation, advocacy, education and training, and information and referral to people with disabilities, their families, and the professionals who serve them. Created in 1975 by Congress in response to a series of investigative reports which exposed abuse and neglect at a New York state institution for individuals with developmental disabilities, a core function of protection and advocacy agencies including Disability Rights NJ is to have a regular, ongoing presence in settings where individuals receive services, and to investigate incidents of abuse and neglect. In this role, Disability Rights NJ has been investigating allegations of abuse and neglect in state developmental centers and state psychiatric hospitals since it was formed in 1994. However, as individuals have moved from institutions into more community settings such as group homes, Disability Rights NJ

Advocating and advancing the human, civil and legal rights of persons with disabilities

has expanded its role to ensure that individuals with disabilities continue to be free from abuse and neglect wherever they might reside.

Disability Rights NJ recognizes the prevalence of abuse and neglect against individuals with intellectual and developmental disabilities. All research shows that individuals with intellectual and developmental disabilities are three (3) to ten (10) times more likely to experience abuse. Individuals who live in settings dependent on round-the-clock caregivers are particularly vulnerable. Disability Rights NJ acknowledges that abuse and neglect must be addressed. However, self-determination and privacy of individuals with intellectual and developmental disabilities must also be protected.

Position Summary

The use of mandated electronic monitoring devices (EMDs) in community settings violates an individual's right to privacy, and there is little to no evidence that the use of EMDs in community settings actually results in less abuse and neglect. In addition to being unlikely to prevent abuse or neglect, the requirement for EMDs in community setting creates new problems. First, the introduction of EMDs in any part of the home conflicts with Medicaid's Home and Community Based Settings Rule due to its failure to ensure the privacy of the individuals. Second, the consent structure contemplated in this draft creates a hostile environment that limits the self-determination of individuals who may or may not want video recording in their home and drives away already scarce staff. Third, the bill will result in unintended consequences that could affect the ability of individuals with

disabilities to have access to a community placement. Fourth, the bill fails to address how the EMDs are monitored, and who has access to the recordings. Finally, we offer that a variety of less restrictive alternative strategies exist that could be implemented to reduce abuse and neglect with fewer unintended consequences. These alternatives include enhancing reporting and oversight and supporting a competent and qualified workforce.

Violation of Home and Community Based Settings Rule

The use of EMDs in community settings brings forth many concerns related to potential human rights violations and other issues that could lead to unintended consequences adversely impacting people with intellectual and developmental disabilities. Individuals with disabilities have been fighting since before *Olmstead v. L.C.* to fully participate in their communities, something others take for granted. A huge step toward integration came with the implementation of the Centers for Medicare and Medicaid Services (CMS) Home and Community-Based Services Settings (HCBS) Final Rule (CMS 2249-F/2296-F). This final rule provides the framework for states to develop a system of community-based services that truly integrate individuals with disabilities into communities and supports them to have the maximum amount of autonomy and independence over their own lives. The Final Rule requires that providers receiving Medicaid HCBS funding to support individuals with disabilities in settings that provide the opportunities and access to the community and “ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint.” EMDs that monitor the individual’s movements and activities in living quarters violate the privacy of the

individual. For example, imagine being under constant surveillance while in your kitchen or living room attending to everyday activities. Even in comparatively segregated, more restrictive Developmental Centers, current CMS rules prohibit EMDs regardless of resident consent. The installation of EMDs in a community setting while being prohibited in a segregated setting violates a core goal of the HCBS rule and jeopardizes Medicaid funding of the myriad services that enable people with intellectual and developmental disabilities to live in their communities.

In addition, the bill as drafted does not offer strong enough protection to ensure that consent is voluntary. Although the bill as drafted requires that consent be given by the legal guardian, there is no requirement that the actual resident be consulted by the guardian or given the opportunity to express their opinion concerning the EMDs. Furthermore, since unanimity is required before action can be taken, the bill creates the potential for coercion from providers and housemates to accept EMDs if the majority requests them. Such coercion violates the HCBS final rule and violates the individual's right to self-determination.

Barriers to Housing and Services

This bill may also have serious unintended consequences. First, the demand for community settings is high, and the number of open beds in the state is low. Once a setting is established as a video-recorded setting, individuals who do not consent to video recording will be discouraged from living there by the authority of this bill, thus limiting their options to select a service provider, and may force individuals to wait longer to receive needed services or

remain in a segregated setting like a nursing home or developmental center. Second, EMDs are expensive to install, and if providers are required to install these systems, the provider will have to reallocate funding from the services it provides its residents. Reallocating funding from direct care poses a myriad of health and safety concerns. Research has shown that a competent and qualified workforce is essential in preventing abuse and neglect.¹ If funding for the EMDs results in less funding for staffing and direct care, the risk for abuse and neglect in fact will rise.

EMD Supervision Issues

Furthermore, the bill as drafted does not address who will be monitoring the EMD, who will have access to the recordings, or how long those recordings will be maintained. EMDs may record the activity in the rooms where they are located, but if no one is always monitoring the video, abuse captured by the cameras may not be prevented. In addition, considering how easy recordings are to post to the internet, it is imperative that legislation requiring EMDs specify which individuals have access to live feeds and recordings.

Alternative Actions to Prevent Abuse and Neglect

Enhanced Oversight

Because abuse and neglect of individuals with intellectual and developmental disabilities is a serious concern, there are other alternative actions that are designed to

prevent abuse and neglect but maintains an individual's right to self-determination, dignity and privacy. First, stronger oversight by state agencies effectively reduces abuse and neglect.

In 2018, at the request of Congress, the Department of Health and Human Services Office of Inspector General (OIG) examined states' monitoring and reporting of injuries and other critical incidents of people with developmental disabilities living in group homes. OIG found that up to 99 percent of these critical incidents were not reported to the appropriate law enforcement or state agencies as required.² To assist states in making improvements, ACL joined OIG and the HHS Office of Civil Rights, along with the U.S. Department of Justice, to develop Model Practices to help address gaps in reporting and monitoring efforts. The joint report found four critical components of health and safety compliance oversight: 1. reliable incident management and investigation processes; 2. audit protocols that ensure compliance with reporting, review, and response requirements; 3. effective mortality reviews of unexpected deaths; and 4. quality assurance mechanisms that ensure the delivery and fiscal integrity of appropriate community-based services.³

In 2017, New Jersey enacted Stephen Komminos' Law which requires enhanced oversight of providers serving people with intellectual disabilities in licensed community settings, including unannounced site visits, 48 hour reporting of suspected incidents, greater transparency in abuse or neglect investigations, notification to guardians of suspected incidents within two hours, and enhanced drug testing protocols of employees. Because this law has only been in effect for a short amount of time, data should be collected to determine

whether the enhanced oversight mechanisms has had any impact on the incidences of abuse and neglect in licensed community settings.

Staff Development and Competency-Based Training

In addition to stronger oversight, a competent and qualified workforce is essential in preventing abuse and neglect. In a study conducted by the Council on Quality and Leadership – CQL⁴ found that through the implementation of ongoing staff development, provider organizations can significantly improve their service provision and health and safety of those they serve. The analysis of Basic Assurances data obtained from 74 human services organizations servicing approximately 8300 individuals with intellectual or developmental disabilities found that ongoing staff development resulted in not only a reduction of emergency room visits and injuries, but also a reduction in instances of abuse and neglect. In 2013, CMS, in collaboration with the former National Direct Service Workforce Resource Center, published *Coverage of Direct Support Workforce Continuing Education and Training with Medicaid Policy and Rate Setting: A Toolkit for State Medicaid Agencies* (CMS, 2013). A year later, CMS established a standard set of *Core Competencies for the Direct Service Workforce* (CMS 2014). These two resources could serve to assist New Jersey in establishing evidence-based processes that contribute to the prevention of abuse and neglect and improve in the quality of life for people with intellectual and developmental disabilities.

Conclusion

Disability Rights NJ understands and shares the desire to protect our most vulnerable citizens. We believe strongly that abuse and neglect must be addressed by strengthening services and training in ways that enhances an individual's rights to participate in the community while maintaining dignity and privacy, a more supportive service culture, competency-based training, and living wages for Direct Support Professionals. Disability Rights New Jersey believes that the privacy concerns along with effective alternatives to prevent abuse and neglect of individuals with intellectual and developmental disabilities outweigh any perceived benefit of EMDs in community settings, and respectfully opposes A4013 as written.

Thank you for the opportunity to provide written testimony regarding this bill. Should you have any questions, please feel free to contact me at gorlowski@drnj.org.

Sincerely,

/s/ Gwen Orłowski

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