



Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

August 4, 2021

Re: A4013 Requires certain group homes to install electronic monitoring devices in communal areas.

Dear Members, Colleagues, Individuals and Friends,

In the community, there are agencies that use surveillance cameras and others that do not. Individuals and family members, therefore, have a choice in choosing which type of home is best for them. ABCD supports the current system of care in NJ that allows free choice and options. What ABCD cannot support is governmental intervention which publicly promotes an intervention, the benefits of which do not reliably outweigh the risks and substitutes the expertise of the people who have devoted their professional lives to serving people with developmental disabilities for someone's "judgement".

Though there have been several changes to A4013 to provide more restrictions to ensure an individual's privacy, the proposed rules still violate their right to privacy and human rights without providing any evidence that cameras do anything to prevent abuse and neglect.

Family members who entrust the care of their loved ones to us should also have the confidence that we will provide appropriate care. ABCD providers who have spent their professional lives unlocking the potential of individuals cannot support an overarching policy that sets additional limits on the individual's homelife. The intrinsic problem is that surveillance is inseparable from privacy. And if surveillance becomes a common factor in their lives, privacy is in danger of no longer being considered the inherent human right of this minority population.

It is extremely distressing that though the most important person in the decision is the individual, the process of the bill's creation may prove the research, that typically there is little attention paid to their perspective and ethical concerns are often superficial.¹ Has anyone asked them what true consent looks like? Will the policy increase stigma? How will the policy impact their freedom? Their dignity? Their privacy? We cannot support a bill wherein the process alone may have failed to recognize the humanity of the men and women who live in our group homes – infantilized, treated as less than human and then told what they should think and do by other adults. Worse still, when individuals with disabilities are disrespected, they are disempowered and more vulnerable to abuse.²

We are also concerned that this bill will limit a person's right to choose to live in a home that does not have cameras. Providers presently have cameras in their homes; this would force others to have them. We suspect that those behind the bill believe that we should all have cameras.

¹ Niemeijer, A. et al (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(7)1129-1142.

² Spitalnik, D. M. (2020) Testimonial on Prevention of Abuse and Neglect of Individuals with Developmental Disabilities. *NJ Legislature, Assembly Human Services Committee*.

The fact that we are still debating about a tool that may make people less safe in their own home under the auspices of preventing abuse and neglect is chilling.

- Pushing perpetrators further into the darkness away from the eyes of dedicated and caring staff.
- Possibly increasing complacency in the group home and in policy.
- Replacing human staff with technology.

We must not rely on subjective sources to develop policy. For safety's sake, research and expertise must rule the day.

According to research, family members generally serve as supports and caregivers throughout the individual's life. Family members are important as collaborators for professionals providing care.³ As a result, not only should they be acknowledged through the provision of increased support, but part of the policy discussion. Regrettably, in the policy arena, collaboration between family members, individuals and providers has broken down. Efforts must be made to repair this chasm and for all to accept the role for which they are suitable for the sake of the individuals and the quality of the lives they lead.

Finally, this bill is about policing people which is the wrong approach to getting the right thing done.

³ Zambrino, N., Hedderich, I (2021) Family Members of Adults with Intellectual Disability Living in Residential Settings: Roles and Collaboration with Professionals. A Review of the Literature. *The Journal of Health Care Organization, Provision, and Financing*, Find in PubMed <https://doi.org/10.1177/0046958021991301>