Alliance for the Betterment of Citizens with Disabilities

Empowering People: Providers Shaping Policies

Humanity Must Remain at the Center of our Business

Camera Surveillance in Group Homes.

May 2020

Summary and Implications

In the community, there are agencies that use surveillance cameras and others that do not. Individuals and families, therefore, have a choice in choosing which type of home is best for them. The Alliance for the Betterment of Citizens with Disabilities (ABCD) supports the current system of care in New Jersey that allows free choice and options. What ABCD does not support is governmental intervention which promotes an intervention that not only does not reliably protect individuals from abuse and neglect but may make individuals less safe and alienated in their own homes.

Background Presentation

There are agencies which provide community services to individuals with developmental disabilities, some of which are members of ABCD, that employ surveillance equipment in their administrative offices, at their entrances and exits to day programs and residences, in their day programs and group homes, and/or when there is evidentiary concern that an individual is at risk. There exists in the New Jersey Division of Consumer Affairs the Safe Care Cam program which since 2017 has enabled citizens suspecting abuse or neglect of their loved ones in a nursing home or group home access to this equipment in order to closely observe interactions with other residents, families, friends and staff. Currently individuals and families have the option to choose programs and residences which provide camera surveillance and if there is reason to believe that there is abuse or neglect in their loved one's group home, access to State resources.

For over a generation, the abuse of people with intellectual and developmental disabilities has been conceded to and has not been eliminated by deinstitutionalization.[1] Individuals have difficulty reporting abuse because of communication barriers, overprotectiveness and powerlessness.[2] Government's inability to ensure full compliance with standards of care has been argued as the reason why families want surveillance in group homes.[3] But a 2017 review of the literature (43 articles) "found no evidence

[1] Horner-Johnson, W.& Drum C.E. (2006). Prevalence of Maltreatment of People with Intellectual Disabilities: A Review of Recently Published Research. *Mental Retardation and Developmental Disabilities Research Reviews, 12, 57-69.*

[2] Cambridge, P., Beadle-Brown, J., Milne, A., Mansell, J., and Whelton, B. (2011). Patterns of Risk in Adult Protection Referrals for Sexual Abuse and People with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities, 24(2), 1180-132.*

[3] Kohl, T. (2002). Watching out for Grandma: Video Cameras in Nursing Homes May Help to Eliminate Abuse. *Fordham Urban Law Journal.* 30(6).

that camera surveillance reliably protects people with disabilities from abuse and neglect in their homes." [4] [5]

The study further points out that there is no evidence that cameras in homes of people with intellectual and developmental disabilities improved functional performance, independence or quality of life. [6] [7] [8] [9] [10] [11] [12] [13] [14] In fact, evidence points to the contrary as surveillance may raise suspicions[15] [16] and fear of litigation by staff [17] [18] [19] [20] [21] [22]and reduce staffing by agencies. [23] [24] [25] [26] [27] [28] [29] In addition, this solution may lead to a false sense of security, "maybe it's not everything, but it is something." When it is, indeed, nothing.

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[4] Chesterman, J. (2016) Office of the Public Advocate, Victoria, Australia. *Australian Society for Intellectual Disability.*

[5] Hayward, B.A. (2017). The Arguments Against Camera and Closed-Circuit Television Surveillance in the Homes of People with Disabilities to Protect from Abuse and Neglect. *Research and Practice in Intellectual and Developmental Disabilities. 4 (2).*

[6] Cottle, S.N. (2004), "Big Brother" and Grandma: An Argument for Video Surveillance in Nursing Homes. *The Elder Law Journal, 12(1)119-148.*

[7] Desai, S. (2009). The New Stars of CCTV: What is the Purpose of Monitoring Patients in Communal Areas of Psychiatric Hospital Wards, Bedrooms and Seclusion Rooms? *Diversity in Health Care, 6, 45-53.*
Ibid.

[8] Gentry, T. (2009). Smart Homes for People with Neurological Disability: State of the Art. *NeuroRehabilitation, 25, 209-217.*

[9] Huang, C.J., and Goldhaber, T. S.(2012). Malicious Meddling or Transparent Tracking? Telecare as a Logical Extension of Modern Communications Technology. *The American Journal of Bioethics, 12(9) 45-59.*

[10] Lyon, D. (2002). Everyday Surveillance: Personal Data and Social Classification. *Information, Communication and Society, 5(2) 242-257.*

[11]Neimeijer, A. et al. (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.*

12. Neijmeijer, A. et.al. (2014). The Use of Surveillance Technology in Residential Facilities for People with Dementia or Intellectual Disabilities: A Study Among Nurses and Support Staff. *American Journal of Nursing,* 114(12), 28-37.

[13]. Sorrel T., and Draper, H. (2012) Telecare, Surveillance and the Welfare State. *The American Journal of Bioethics,* 12(9) 36-44

[14] Godwin, B. (2012). The Ethical Evaluation of Assistive Technology for Practitioners: A Checklist Arising from a Participatory Study with People with Dementia, Family and Professionals. *Journal of Assistive Technologies.* 6(2)123-135.

[15] Desai, S.

[16] Niemeijier, A., et al. (2013).

[17] Bharucha. A.J. et al (2006). Ethical Considerations in the Conduct of Electronic Surveillance Research. *Journal of Law, Medicine and Ethics, 34(3), 611-619.*

[18] Cottle, S.N.

[19] Gelbart, B. et al. (2009). Ethical and Legal Considerations in Video Recording Neonatal Resuscitations. *Journal of Medical Ethics, 35, 120-124.*

[20] Kohl, T.

[21] McMillan, I. (2003). "Big Brother" Images Conjured Up by CCTV Observations. *Mental Health Practices, 7(1)6.*

[22] Neimeijher, A., et al., (2014).

[23] Cottle, S.N.

[24] Desai, S.

[25] Gentry, T.

[26] Huang, C.J. and Goldhaber, T.S.

[27] Lyon, D.

[28] Niemeijer, A. et al. (2013) (2014).

[29] Sorrell, T. and Draper, H.

If we want to decrease abuse and neglect among individuals with intellectual and developmental disabilities, we must consider the environment and culture[30] in which service is provided rather than summarily build a system of separation, less communication and more hostility. This is not a recipe for safety, let alone for a comfortable and nurturing home life. Quality assurance methods are key to improving and sustaining the quality of the service. Methods include understanding the core aspects of care in the home, setting quality benchmarks, measuring quality, performing audits and supervision. Together these will maintain the delivery of quality care and services and provide confidence that requirements will be fulfilled.

Direct Support Professionals have a great influence on the quality of life of the individual. These essential employees who are predominantly women of color working 2 jobs to support their families, [31] put their health and lives on the line coming to work during the pandemic; taking an enormous risk so that others could stay home. In the system of quality, they must continue to receive training, supervision and rewards for their good work and compassionate care, in addition to a livable wage. Make no mistake, the lion's share of these women and men also work out of love.

The most important person in this discussion is the individual. Typically, there is little attention paid to their perspective and ethical concerns are often superficial.[32] What does true consent look like for you? Will this policy increase stigma? How will this policy impact your freedom? Your dignity? Your privacy?

We must recognize the humanity of the women and men who work in our group homes as well as the humanity of the women and men who live in our group homes. We must resist the temptation to do what is easy, relying on subjective sources to develop policy and on the unquestioning belief in cameras to increase safety.[33] [34] [35] [36] [37]

Conclusion.

Since 1995, ABCD has represented social service agencies in New Jersey that provide an array of community-based services for individuals with complex developmental disabilities. This translates into hundreds of years of expertise working primarily with individuals who have significant communication barriers. We must be careful not to substitute the expertise of the people who have devoted their lives to serving people with complex developmental disabilities for someone's "judgement."

Currently there exist agencies, families and individuals who choose to use surveillance technology.

What ABCD cannot support is governmental intervention through statute, regulation, guideline or norm which publicly promotes an intervention the benefits of which do not outweigh the risks. Surveillance

[30] Hayward, B.A.
[31] PHI, Quality Care Though Quality Jobs. (2018) *It's Time to Care: A Profile of America's Direct Care Workforce.*
[32] 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 Psychogeriatics, 22(7) 1129-1142.*
[33] Cottle, S.N.
[34] Desai, S.
[35] Hood, J. (2003). Closed Circuit Television Systems: A Failure in Risk Communications? *Journal of Risk Research, 6(3), 233-251.*
[36] Minuk, L. (2006). Why Privacy Matters: The Case Against Prophylactic Video Surveillance in For-Profit Long-Term Care Homes. *Queens Law Journal,* 32, 224-277.
[37] Neyland,D. (2004). Closed Circuits of Interaction? The Mobilization of Images and Accountability Though High-Street CCTV. *Information, Communication and Society,* 7(2) 252-271.

cameras not only do not reliably protect individuals from abuse and neglect but may make individuals less safe and alienated in their own homes.

The effort to ensure safety need not and must not insult staff nor turn an individual's life into an open book.

Humanity must remain at the center of our business.

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