

*PRIVACY AND DISABILITY**(A HALF-BAKED INTRODUCTION)*

PRIANKA NAIR

In February 2008, a California judge placed Britney Spears under conservatorship based on her mental health and substance abuse issues, granting oversight of her personal life and finances to her father, James P. Spears. While petitioning for the removal of the conservatorship, Ms. Spears made a twenty-three minute statement to the Court. Her testimony exposed the lack of privacy and the constant surveillance that she endured over 13 years:

They all lived in the house with me – the nurses, the 24-7 security...they watched me change every day – naked – morning, noon and night. My body – I had no privacy for my room, I gave eight gals of blood a week.¹

The conservatorship permitted intrusion into the most intimate provinces of Ms. Spears’ life. The powers granted to her father permitted him to make all personal and medical decisions for her. As a result, she had limited ability to choose her medical treatment or service providers. She described being placed on lithium, which she describes as “a very, very strong and completely different medication compared to what I was used to.” She also described the control her conservator exercised over her ability to get married and have children in refusing to permit her to remove her IUD – a situation that Alexis McGill Johnson, the president and CEO of Planned Parenthood, has described as “reproductive coercion.”

The iron-fisted control and abuse endured by Britney Spears is striking and devastating. However, for many people with intellectual and developmental disabilities, surveillance and lack of privacy are an ordinary part of their lives. Indeed, the idea for this article was born out of the experience of my clients with disabilities of being watched and assessed, not just by courts and state agencies, but by family members, doctors and psychologists, agencies tasked with providing services and even members of the public. The experience of being scrutinized is not limited to guardianship or conservatorship. Parents with disabilities represented by the Brooklyn Law School Disability and Civil Rights Clinic as part of its family defense practice are subject to constant and intense scrutiny. The inability to “control” or “manage” a child during a supervised visit could result in the parents being written up as being unable to parent. This scrutiny permits the state to engage in constant punishment for

*Assistant Professor of Clinical Law, Brooklyn Law School

¹ Julia Jacobs and Sarah Bahr, *The Britney Spears Transcript, Annotated: ‘Hear What I Have to Say’*, THE NEW YORK TIMES (June 24, 2021), <https://www.nytimes.com/2021/06/24/arts/music/britney-spears-transcript.html>.

perceived parenting flaws. Surveillance also occurs over the most intimate aspects of the lives of people with disabilities. Adults with intellectual disabilities living in group homes are subjected to discriminatory policies that suppress their sexual rights through constant monitoring and regulation.²

This article will consider the impact of this constant surveillance, namely, the loss of privacy. Privacy has been described as freedom of thought, control over one's body, solitude in one's home, control over personal information and protection from searches and interrogations.³ Other commentators have moved towards a more functional definition of privacy that focuses on the goals that privacy helps accomplish, not least of which is a democratic society peopled with autonomous and thoughtful citizens.⁴ Privacy has also been linked to creativity and personhood.⁵ Although the word is never specifically mentioned, privacy is protected by the U.S. Constitution. The Supreme Court has recognized that the Fourth Amendment protects against government searches where a person has a "reasonable expectation of privacy."⁶ Additionally, the Supreme Court has held that the Constitution preserves "a zone of privacy" encompassing decisions people make about sexual conduct, birth control and health.⁷

Koops et al.⁸ have compiled a typology of privacy by conducting a systemic analysis of the constitutional protections of privacy in nine jurisdictions, including the US, Canada and the UK. They note that privacy can be characterized in negative terms - as protection from governmental or external interference. These categories of privacy include bodily privacy (namely, the negative freedom to exclude people from touching one's body or restricting or restraining one's bodily movement) and spatial privacy (an interest in preventing access to one's private space, like the home, and private activities that may occur in such a space).⁹ Other categories of privacy are positive - with an emphasis on freedom and self-development. These include intellectual privacy (typified by privacy of thought and mind and the development of opinions and beliefs), decisional privacy (typified by intimate decisions, primarily of a sexual or procreative nature), associational privacy (one's interests in being free to choose who they wish to interact with) and behavioral privacy (typified by the privacy interests that a person has while conducting

² Natalie M. Chin, *Group Homes as Sex Police and the Role of the Olmstead Integration Mandate*, 42 N.Y.U. Rev. L. & Social Change 379, 383 (2018).

³ See e.g. DANIEL SOLOVE, UNDERSTANDING PRIVACY, 7 (2014) ("Privacy seems to encompass everything, and therefore it appears to be nothing in itself.").

⁴ Ruth Gavison, *Privacy and the Limits of the Law*, 89 Yale L.J. 421, 442 (1980). See also KHIARA M. BRIDGES, THE POVERTY OF PRIVACY RIGHTS, 154 (2017) (writing that privacy is central to the ability of an individual to make autonomous decisions).

⁵ *Id.* at 442.

⁶ *Katz v. U.S.*, 389 U.S. 347 (1967).

⁷ *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965).

⁸ Bert-Jaap Koops, Bryce Clayton Newell, Tjerk Timan, Ivan Škorvánek, Tomislac Chokrevski & Maša Galic, *A Typology of Privacy*, 38 U.P.A. J. INT'L L. 483, 567 (2017).

⁹ *Id.* at 568

publicly visible activities).¹⁰ Although this is subject to change, these are these “positive” categories of privacy are the ones that I am especially interested in.

Historically, society has not prioritized the protection of privacy of people with disabilities, particularly intellectual and developmental disabilities (I/DD), and psychiatric disabilities. Warehoused in conditions that exposed them to near constant scrutiny, people with disabilities were frequently subject to laws and regulations that actively deprived them of control over decisions that have been recognized as falling within the sphere of privacy. This includes decisions about bodily autonomy, family planning and medical intervention.

As society moves away from segregation and towards community integration, questions of privacy taken on a particular salience. The privacy interests of people with disabilities (particularly intellectual, developmental and psychiatric disabilities) are often sidelined or subordinated to other interests. The systems that govern the lives of many people with intellectual, developmental, and psychiatric disabilities do not have robust privacy norms embedded in them. To some extent, this may be unavoidable. Information about an individual may be necessary to develop appropriate community-based supports and services for the individual. This may require disclosure of information that is very intimate in nature, including the person’s ability to toilet or bathe themselves. It is arguable that such incursions into privacy are less harmful and are even beneficial, in protecting the dignity and well-being of people with disabilities. However, that there are circumstances where the deprivation of privacy is driven by misconceptions about people with disability, including the belief that people with disabilities require special or extra protection. This can have the effect of expanding and legitimizing further marginalization of people with disabilities.

Part II of this article will address the complex relationship between privacy and disability. Privacy is not an unqualified good, and indeed, has been used as pretext to shield abuse and neglect from public view. Scholars have argued that privacy around the disclosure of disability has led to impoverished public narratives about disability, perpetuating stigma around disability.¹¹ However, a nuanced approach to privacy must also recognize what privacy enables – including the ability to develop intimate relationships, act autonomously, and develop a sense of self. This part advances the argument that there is value in protecting the privacy of people with disabilities, and harm in failure to do so.

Part III will consider some examples of regulatory systems that promote incursions into the privacy of people with disabilities and the norms that drive the deprivation of privacy.

¹⁰ *Id.*

¹¹ *See generally*, Jasmine E. Harris, *Taking Disability Public*, 169 U. Pa. L. Rev. 1681 (2021).

An example of such a regulatory system is guardianship. Guardianship laws are structured so that every decision made by the individual under guardianship is subject to scrutiny. This is inherent in the way guardianship laws are constructed - the label of incapacity appears to permit intrusion into all aspects of the life of the individual by the guardian. Guardianship proceedings frequently hinge upon a finding of incapacity. As such, once one is found incapacitated, courts tend to transfer broad authority to guardians. Guardians frequently assume broad powers – all the decisions that “define who we are as human beings,” including “where and with whom we live, whether we can travel, marry, engage in certain social activities or interactions; whether we accept or reject medical treatment; and whether and how we manage our income and resources.”¹² Given the responsibility given to the guardian, they bear the responsibility of being in a fiduciary relationship to the ward and must act in either their best interests or with knowledge of what that individual would want. Indeed, a good guardian must know and understand all aspects of an individual’s life to execute their duties effectively. Respecting privacy simply has no place in a guardianship regime.

Another example is the extreme visibility that people with disabilities endure in public – a visibility that exposes them to disability discrimination. Deeply entrenched views about the association between disability and criminality and the conflation of disability related behavior with dangerousness have also encouraged and justified this surveillance. As Professor Jamelia Morgan has pointed out, if one of the aims of policing is to minimize public disorder, and disability related behavior is perceived or constructed as being suspect and violative of public order, then surveillance of people with disabilities may simply constitute good policing.¹³ The deprivation of privacy in public – what Koops et. al refers to as behavioral privacy – often has fatal consequences. As Camille Nelson notes, “Despite the potential inability of a mentally-ill person to comport his or her behavior, the police are privileged to use the force necessary to overcome a lack of cooperation.”¹⁴

A final example that I will proffer here is the lack of associational privacy that people endure in congregate care spaces that many people with intellectual, developmental and psychiatric disabilities endure. Professor Elizabeth Emens notes that the law’s express role in managing intimate relationships has been

¹² Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making As a Violation of the Integration Mandate of Title II of the Americans with Disabilities Act*, 81 U. Colo. L. Rev. 157, 167 (2010).

¹³ Jamelia Morgan, *Rethinking Disorderly Conduct*, 109 Cal. L. Rev. 1637, 1673 (2021) (“Responding to mental episodes by bringing disorderly conduct charges—whether the resulting charge leads to physical removal via citation or arrest—conveys the social message that individuals with psychiatric disabilities are disorderly, violent, or prone to violence and criminality. These social meanings in turn reinforce existing justifications for responding to mental episodes with law enforcement rather than with public health approaches.”).

¹⁴ Camille A. Nelson, *Racializing Disability, Disabling Race: Policing Race and Mental Status*, 15 Berkeley J. Crim. L. 1, 43 (2010).

to prevent them from occurring.¹⁵ This is particularly true for people with disabilities. She writes that a core story of disability is isolation in an institution.¹⁶ As such, the forming of intimate relationships alone is a significant deviance from the societal narrative about disability.¹⁷ In the eyes of the law, intimacy and disability have been seen as incongruent with each other. Continued concerns about the consequences of people with disabilities being able to live with, sleep with and procreate continue to animate regulations that govern group homes that many people with disabilities live in. While OPWDD regulations explicitly recognize that one is entitled to education about sex and reproduction, they do not recognize the need for privacy in any meaningful way to develop intimate relationships or to plan for the creation of families. Indeed, the system of behavioral management mandated by the regulations spur the ongoing monitoring and management of the bodies in these group homes.¹⁸

Part IV will outline the implications of this approach, particularly the impact of privacy deprivation on the goal of integrating people with disabilities into society. Specifically, my focus here is on the goal of integration. The ADA recognizes the long history of the segregation and marginalization of people with disabilities. The integration mandate of the ADA seeks to ensure that people with disabilities have opportunities to live, work and receive in the greater community, like individuals without disabilities. Without the space to develop relationships, exercise decisional autonomy, and exist in public spaces without punitive intervention, it is questionable just how effectively the goal of integration can be achieved.¹⁹

Part V will also outline prescriptions to correct the trajectory. The call for the protection of privacy, I believe, is inherent in concepts that have already been adopted by the disability rights movement. Take, for instance, supported decision making as an alternate to guardianship. The retention of agency in supported decision-making models limits curial scrutiny into all aspects of an individual's life and allows the individual to control the use and dissemination of their information. The protection of the privacy of the individual is an important part of what supported decision making protects. Similarly, the notion of the least restrictive intervention protects a sphere within which the

¹⁵ Elizabeth Emens, *Intimate Discrimination: The State's Role in the Accidents of Sex and Love*, 122 Harv. L. Rev. 1307, 1315 (2009)

¹⁶ *Id.* at 1338.

¹⁷ *Id.*

¹⁸ LIAT BEN-MOSHE, *DECARCERATING DISABILITY: DEINSTITUTIONALIZATION AND PRISON ABOLITION*, 77 (2020).

¹⁹ Jacobus tenBroek, *The Right To Live in the World: The Disabled in the Law of Torts*, 54 CAL. L. REV. 841, 918 (1966) (“The right to live in the world consists in part of the right to live out of it. The blind, the deaf, the lame, and the otherwise physically disabled, have the same right to privacy that others do; not only the right to rent a home or an apartment, public or private housing, but the right to live in it; the right to determine their living arrangements, the conduct of their lives; the right to select their mates, raise their families, and receive due protection in the safe and secure exercise of these rights.”)

individual is given the freedom and the privacy to make their own decisions. I am still thinking about and developing these ideas and would appreciate any guidance on how to think about this section of the paper.