

DIGNITY OF RISK AND LIVING AT HOME DESPITE SEVERE DISABILITY

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ABSTRACT For Americans with significant disability, decisions about where to live are common flashpoints for the dignity of risk principle. Typically, a health-care professional, like the person's primary care physician, argues that the person is unsafe living at home and therefore must enter a nursing home. However, most people—even with extensive activities of daily living support needs—want to remain home in their communities. The belief that nursing homes offer safer residential environments is unproven and highly suspect. Furthermore, removing people from their personal home comforts diminishes their quality of life. Nonetheless, despite the clear moral imperative of the dignity of risk principle, many factors in the United States impede people with significant disability from remaining at home. Ableist and stigmatized attitudes of physicians about quality of life among people with disability are potential contributors. Few people have adequate financial resources to afford the personal assistance services (PAS) they need for daily basic supports. Medicaid, the major public payor for PAS, is difficult to join, varies widely by state, and has long waiting lists for home and community-based services. These issues are explored using stories from the author's friend Michael, who has significant physical disability and lives home alone.

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Perspectives in Biology and Medicine, volume 65, number 2 (spring 2022): 252–261.

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“**Y**ou are not safe at home. We need to put you into a nursing home.” These words encapsulate the fears dogging Americans with significant disability who are living in their homes but without adequate personal resources to hire the assistance they need to support activities of daily living (ADL). Although precise numbers are unknown, anecdotal reports suggest that many people with significant disability but without a robust network of informal caregivers share this worry. Sometimes, these fears become reality. Powerful practical pressures build to force them from their homes and communities into nursing homes. Although the dignity of risk principle has a clear moral imperative, supporting their right to remain in their homes, achieving this end confronts daunting financial, health-care delivery system, and other barriers.

This scenario—questioning the safety of people living at home—has long been recognized in the context of older people who are frail and socially isolated (Maitland 2012). Typically, an older person experiences a significant acute health setback, such as hip fracture or heart attack, and then various health-care professionals assess whether the person can safely live at home. In these instances, providers typically aim to balance patients’ autonomy against their professional obligations of beneficence, often shadowed by doubts about the older person’s decision-making capacity (Collopy 1995). For older people who want to remain in home environments that others consider unsafe, sometimes that supposed “ecentricity” is viewed as confirming mental incapacity (Collopy 1993, 94). Beneficence requires providers to focus on maximizing the presumed well-being of their patients. These professionals might experience “moral pain” when patients fail to follow their advice (95). Nonetheless, principles of beneficence preclude health-care professionals from abandoning nonadherent patients.

The issues are more complicated for older persons than this brief summary implies. And considering younger persons with lifelong or long-lasting disability, who might live for decades, magnifies this complexity. Principles of independent living frame this issue around dignity of risk, which is closely related to the autonomy principle. The motivations of people with disability to remain in their home and communities—rather than moving into nursing homes—are typically obvious, starting with preserving dignity. Practical impediments nevertheless present almost insurmountable hindrances to attaining this goal. Unless people have family or friends willing to forgo their own livelihoods to provide in-home ADL supports, people with significant disability must rely on paid personal assistance services (PAS). PAS is not covered by either Medicare or private insurers, leaving Medicaid as the only major public payor for home-based PAS. However, obtaining Medicaid coverage is difficult, and Medicaid PAS policies vary widely across states. Furthermore, even when states provide home and community-based services (HCBS), long waiting lists prevent many Medicaid beneficiaries from obtaining these supports. In 2017, more than 707,000 Medicaid beneficiaries were on HCBS waiting lists across 40 states; about two-thirds were individuals with

intellectual or developmental disabilities, and 28% were older persons or people with significant physical disability (Musumeci, Chidambaram, and Watts 2019).

Beyond costs, the attitudes of health-care professionals involved in decision-making about where people should live can be complex. Beneficence might be a factor, but even health-care professionals without extensive knowledge or the lived experience of disability themselves may have little appreciation of how people with disability adapt to their environments—the so-called “disability paradox” (Albrecht and Devlieger 1999). Furthermore, the safety of residential environments—especially for people with significant ADL support needs—is not an absolute. Although nursing homes may address certain health-care needs, such as medication administration, they may have insufficient staff to reliably support basic ADLs.

Numerous powerful factors may therefore prevent people with significant disability from achieving their goals about living at home under the dignity of risk principle. With his permission, I explore these complex motivations using stories relating to my friend Michael, who has complete quadriplegia and lives alone. He escaped from efforts to involuntarily move him into a nursing home, but with significant negative long-term effects.

INTRODUCING MICHAEL

I met Michael on the train platform at Princeton Junction, New Jersey, in late October 2009, the day my scooter-type wheelchair died (Iezzoni 2019). I began using this scooter in 1988 as my relapsing-remitting multiple sclerosis (MS) became secondary progressive. I had flown from Boston to attend a meeting in Princeton, and this ancient scooter officially died at Newark Airport. Train conductors pushed the dead scooter and me, unable to walk, onto the westbound train, and at Princeton Junction Station, pushed me off. Seeing I was in trouble and wanting to help, a man came up to me. He stayed with me for 45 minutes on the platform, as through trains whizzed terrifyingly by, the sun set, and evening chill fell, until the car the meeting organizers sent arrived to take me away.

That man was Michael. His head twisted rightward with torticollis, he operated his power wheelchair’s joystick with his right hand, his spastic left arm tightly gripped his chest, and his legs and feet were completely still. His mind is sharp and clear, and he is a problem solver. Then age 55, Michael’s primary progressive MS (PPMS) had been diagnosed at age 42 and forced him at age 50 to retire from work as an Oxford University-trained physicist (he was born in England). Divorced, he lived alone but had spent considerable effort fully adapting his modest home, with ceiling-mounted automated lifts, accessible bathroom, ramps, and other accessibility features. He lived a rich life, auditing courses at the local university, attending concerts, and leading occasional cooking demonstrations at the summertime farmer’s market. Shortly after our friendship began, I became Mi-

chael's health-care proxy and advocate, first supporting him through successful surgery for a stage 4 pressure injury (pressure ulcer) (Iezzoni 2019; Iezzoni and Ogg 2012).

MICHAEL'S CLINICAL TEAM AND IN-HOME SERVICES AND SUPPORTS

In addition to specialists (neurologist, physiatrist, urologist), Michael needs a primary care physician (PCP) to oversee his care, provide screening and preventive services, and address episodic acute care needs, such as urinary tract infections. He also needs home nursing visits to manage his suprapubic tube and monitor his skin integrity. Michael does not have family or friends to support his ADLs and instrumental ADLs (IADLs, such as shopping, meal preparation, laundry, light housework). To live independently in his home, Michael's most essential need is therefore paid PAS (Iezzoni 2022).

For several years, Michael had obtained paid PAS from a commercial franchise PAS agency (Ogg 2011). However, he eventually could not afford to pay agency fees for the PAS required to meet his increasing needs. I recommended that he explore joining the local Program of All-Inclusive Care for the Elderly (PACE). This program aims to support Medicare and Medicaid beneficiaries age 55 and older with extensive chronic health problems or severe disability to remain in their homes and communities. PACE transports its typical participants on weekdays to adult day care, returning them home at night to their families. PACE also provides in-home PAS, as needed. Michael would not attend adult day care, preferring to remain active in his community, but otherwise he seemed a perfect PACE candidate.

Not all PACE clinical leaders agreed. "I later heard whispers," Michael recalled, "that some [PACE providers] felt that, especially since I lived alone, I was too disabled for [them] and belonged in a nursing home" (Ogg 2019, 1047). Nevertheless, for four years PACE worked well for Michael. With 10 hours of PAS daily—70 hours per week—he was happy overall with his ADL and IADL supports.

WARNING SIGNS

A couple years into Michael's PACE enrollment, warning signs appeared about whether PACE would support his remaining at home. Michael developed severe neurogenic pain, controlled only by twice-daily medications. Although his state had relaxed the nurse practice act regulations that restrict medical tasks that non-licensed personnel can provide, his PACE would not allow PAS providers to administer medications—they required a home visiting nurse to give him the pills. "My nurse told me that if I needed twice-daily medications," Michael recounted, "they might have to put me in a nursing home instead of sending the

home nurse twice a day”—and thus increasing his costs (Ogg 2019, 1047). Michael engineered a workaround. He had a flexible metal gooseneck rod clamped to his kitchen counter with a plastic drinking straw taped to its free end. “The daily morning nurse put my evening tablet in the straw tip, so that I could later position my wheelchair in front of the straw and take the tablet in my mouth.” PACE allowed his evening PAS worker to give him sips of water so he could swallow the pill.

PACE PUTS MICHAEL IN A NURSING HOME

Michael’s PACE denouement started in late spring 2017, when his wheelchair’s circulating air cushion was sent for repairs. For several days Michael sat on a cushion without adequate pressure relief and developed a small pressure injury. For the next month, PACE home care nurses visited him daily, treating his wound and asserting it was steadily healing. After a month, Michael’s PACE PCP transported him to their health center for an examination, and several days later, without consulting Michael, she sent an ambulance to his home to take him to a nursing home. The PCP prescribed complete bed rest and turning every several hours to treat the pressure injury.

Although Michael’s nursing home experiences were deplorable, after several weeks the pressure injury improved, and an expert wound care nurse practitioner told him he could return home with daily nursing to recover fully. Nevertheless, almost a month after his nursing home admission, Michel’s PACE PCP came to his room and told him she would not allow him to go home, either then or in the future. Without offering any evidence, the PCP said he was unsafe living at home. PACE would not restart his PAS or home nursing visits if he left the nursing home. Michael could appeal the PCP’s decision to a Medicare adjudicator, but during that lengthy administrative process, PACE would keep Michael involuntarily in the nursing home. When Michael submitted the appeal, the PCP declared the “therapeutic bond broken”; she never again saw Michael.

Michael has written about what happened next and the effects on his health and well-being (Ogg 2019, 2020). Once the nursing home physician declared his pressure injury healed, staff stopped turning him in bed and monitoring his skin integrity. He “grew increasingly despondent, losing hope. With a patient-to-certified nursing assistant ratio of 10 to 1 and my complete quadriplegia, nursing home staff neglected my most basic needs. I was hungry, thirsty, unwashed, unshaven, untoileted, and despairing. I lost all dignity and self-respect” (Ogg 2019, 1047). Even when the Medicare adjudicator ruled in Michael’s favor, instructing PACE to send him home with the same PAS as before, PACE refused to budge; appealing the adjudicator’s ruling, they indicated they would keep Michael in the nursing home during the appeals process. Michael only left the nursing home when he became dangerously ill, and then they transferred him to a hospital. In addition to his extreme dehydration, staff there found extensive skin macera-

tion and new pressure injuries—the nursing home had neglected skin checks for weeks.

Michael and I never understood what motivated his PACE PCP to keep Michael involuntarily in the nursing home and then stand by while the nursing home threatened his health. He disenrolled from PACE while in hospital, refusing to return to the nursing home while PACE's appeals process played out. Michael did win his appeal several months later, after he had left PACE.

FINDING A NEW PCP

The hospital effectively treated Michael's infection and started the process for addressing his macerated skin and new pressure injuries. However, before he could return home, the hospital required that he have supports in place, including a new PCP. Several days after his hospital admission, I trained down to visit Michael and watched with mounting alarm as hospitalist after hospitalist stood, arms folded, at the foot of his bed, voicing hesitation about discharging him home. The following week, from a 250-mile distance, I took on the job of finding his new PCP.

Depending on where you live, locating a PCP these days is challenging at best. Identifying a PCP willing to accept complex patients like Michael presents even greater difficulties. Through my professional network, I unearthed several names, including one PCP highly recommended for both her exceptional patient-care skills and personal qualities. But my conversation with her did not go well. She immediately questioned the wisdom of sending Michael home and pointedly balked at my asking her to support his goal against her professional judgment. I tried to explain the PAS supports that Michael would have, his accessible home, and his clear-headed weighing of his options. But her mind was made up. She indicated it was unfair to question her professional opinion, however hastily made, which she thought put her in the awkward position of providing care she viewed as inappropriate. She would not become Michael's PCP.

I eventually did find Michael a new PCP—a recently minted geriatrician, just starting her career. She provided meticulous care with endless empathy, making decisions collaboratively with Michael. Several years later, she told me how much Michael had taught her and the students she brought with her on home visits, lessons that would inform their future practices.

DISCUSSION

The dignity of risk principle clearly upholds Michael's preference to live home alone despite severe disability. He thoroughly appreciates his risks and has made substantial efforts to mitigate those risks. He has spent considerable resources adapting his home, making it safer not only for himself but also for his PAS staff. He loves his home and being surrounded by those comforts which maximize

his quality of life. Nevertheless, despite the moral imperative of the dignity of risk principle, Michael's story suggests the many forces that conspire against the decision to live home with significant disability. The first is attitudes of physicians, like his PACE PCP, about people with disability. A 2019–2020 nationwide survey of practicing US physicians found that 82% believe that the quality of life of people with significant disability is worse than that of nondisabled people (Iezzoni et al. 2021). If physicians implicitly or explicitly view the lives of people with disability as low quality, this can undoubtedly affect their attitudes about patients' choices concerning how they want to live those lives.

Caring for a patient who disagrees with their judgment is a common occurrence for PCPs—smokers not quitting, people not exercising—and most seem to take this nonadherence in stride. While regretting such decisions (smoking is clearly bad, and exercise is good), most physicians do not take these rejections of their advice personally and abandon their patients. Choice of residential setting is certainly a major decision, but as Michael's experiences show, a nursing home was not safe for him. The federal government and most states have so-called “conscience laws,” which protect physicians, institutions, and others from being required to perform services they find morally objectionable (Sawicki 2018, 2019). Although Michael's situation does not precisely fit these conscience arguments, maybe physicians could legitimately claim that being required to provide care against their professional judgment harms them. Assessing the validity of this claim, however, seems inextricably linked to their professional judgment being sound: the nursing home had clearly injured Michael, and twice the Medicare adjudicator ruled he should go home. In addition, the principle of beneficence—presumably compounded by empathy—enjoins health-care professionals from abandoning patients who reject their recommendations (Collopy 1993).

The well-known litigiousness in US medicine might also color physicians' attitudes about people with disability living at home, especially alone. Physicians might fear that if something goes wrong for their patient at home, the physician might be blamed. Countering that concern is the likelihood that physicians would extensively document patients' medical records, indicating that patients made the decision against physicians' explicit advice. Perhaps physicians also worry about reputational damage: that their colleagues would criticize them if their patient with significant disability went home and something catastrophic happened.

Maybe ableist attitudes and implicit disability bias can prompt physicians to feel strongly and without self-reflection that their judgments are superior to the views of their patients with disability. Convinced of their rectitude, physicians—like Michael's PCP—might view a decision like where to live as a test of will or authority. But these attitudes go against a touchstone of high-quality care, ensuring person-centeredness (Berwick 2002). They also contradict one of the three fundamental principles of the Charter on Medical Professionalism:

Principle of patient autonomy. Physicians must have respect for patient autonomy. Physicians must be honest with their patients and empower them to make informed decisions about their treatment. Patients' decisions about their care must be paramount, as long as those decisions are in keeping with ethical practice and do not lead to demands for inappropriate care. (ABIM et al. 2002, 244)

Michael's request to go home was clearly appropriate: Medicare's adjudicator upheld his preference twice.

Michael and I speculated that financial concerns might have influenced his PACE PCP. A common assumption is that keeping people at home will save costs. However, that may not always be true. For example, in 2020, the median hourly wage was \$13.02 for personal care aides (US Bureau of Labor Statistics 2021). Today, Michael needs 19 hours daily of PAS. Based on these national median numbers, wages alone for PAS providers would annually cost about \$90,325, before factoring in federal and state employment taxes, home-based professional services (from licensed nurses and rehabilitation therapists), and administrative costs of his Medicaid health plan. Medicaid generally pays only for shared rooms at nursing homes, and average 2020 shared-room nursing home costs across the US were \$93,075 (ACOA 2021). Thus, it might be cheaper for Michael's Medicaid program to keep him in a nursing home rather than provide the home-based supports he needs.

The seminal 1999 ruling of the US Supreme Court in *Olmstead v. L.C.* (527 U.S. 581 (1999)) found that, under Title II of the Americans with Disabilities Act (ADA) of 1990, people with disability have the civil right to live in community settings rather than institutions. However, individual states have invoked fiscal concerns when confronted with expanding Medical HCBS expenditures. In its Supreme Court arguments, Georgia—the state at issue—asserted that it did not have sufficient Medicaid funding to support the two women litigants in the community rather than in institutions. In writing the *Olmstead* decision, the late Justice Ruth Bader Ginsburg recognized these financial concerns and tried to walk a fine line, giving Medicaid programs the guidance to make measured but steady progress toward deinstitutionalization. For instance, Justice Ginsburg's opinion noted that states could put institutionalized people on waiting lists for community-based services, so long as those waiting lists moved along at a reasonable pace. The ruling did not specify what constitutes an acceptable waiting period. In 2017, Medicaid HCBS waiting lists averaged 30 months, although this varied by population (varying from four months for programs for people with HIV/AIDS to 66 months for programs for people with intellectual or developmental disabilities) (Musumeci, Chidambaram, and Watts 2019).

Furthermore, in her *Olmstead* opinion, Justice Ginsburg qualified this civil right of people with disability, deferring to "medical professionals" to decide whether a person with disability could live in the community with appropriate supports. Disability advocates voiced dismay about deference to physicians in the

Olmstead ruling, observing that most physicians know little about how people with disability live in their homes and communities. The US Department of Justice Office of Civil Rights (2011) issued technical guidance about the evidence required to demonstrate that people with disability can live in communities under *Olmstead*. It stated that physicians' opinions are only one form of evidence: "people with disabilities can also present their own independent evidence of the appropriateness of an integrated setting." Thus, under *Olmstead*, Michael clearly had the legal right to make this decision for himself. However, given its discharge policies, he could not leave the hospital without an assigned PCP.

CONCLUSION

Dignity of risk is a powerful principle, foundational to the independent living movement. However, in the context of decisions about where to live for people with significant disability, making the dignity of risk principle stick confronts powerful challenges. Ableist and other biased attitudes among physicians are one potential problem. A possibly insurmountable practical problem involves cost: in-home supports for people with significant ADL needs is expensive, and few people have the resources to pay for these services themselves. In a 2021 guest essay in the *New York Times*, disability rights advocate Ady Barkan, who is severely disabled from amyotrophic lateral sclerosis, eloquently made this point: "Without home care, I would have to be in a nursing home to stay alive. And to be honest, I don't know if that would be a quality of life that I would be willing to tolerate." His "brilliant wife" and two small children enrich his daily existence—he has a "beautiful life."

Barkan has worked out special arrangements to cover his seven-member in-home PAS team, but he notes that "across the country, almost a million children, adults and seniors with disabilities sit on waiting lists for Medicaid's home- and community-based care, in danger of being removed from their homes and sent to live in institutions." Medicaid rules prevent beneficiaries, like Michael, from making the financial arrangements that Barkan has orchestrated to support his PAS needs. As Barkan suggests, society—and thus inevitably the federal and state governments—must step in to eliminate the overwhelming financial barrier to people with disability who choose to live home alone, being able to achieve their goal. As Michael's story suggests, changing attitudes among health-care professionals about this issue remains a work in progress.

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