Bringing Vincent Home

When the wife’s developmentally disabled brother moves in, a couple discovers some realities of daily life in the U.S. social service system.

by Veronica P. Pollack and Harold A. Pollack

Vincent and Janice had a routine. Vincent refused to go to bed until his mother was safely tucked in. If Janice stayed up to work or watch television, he would sit nearby, insistent and bleary-eyed, until she went to bed. On the days Vincent’s sheltered workshop was closed, he would sit quietly next to Janice at the travel agency while she worked. Saturday was their day for lunch out, followed by shopping. They went everywhere together, even on trips to Orlando and Las Vegas.

For almost forty years, Janice cared for Vincent, her developmentally disabled son, at home. Then she died suddenly in February 2004. Because Veronica is Vincent’s only sibling, Vincent joined our home. This marked our rude introduction to our nation’s care systems, systems that are sometimes surprisingly generous yet often unable to serve families well.

Vincent’s Early Life

Living in upstate New York with Janice, Vincent led a quiet life with little outside contact aside from his training workshop operated by the local Association for Retarded Citizens (ARC). Janice, a smart and capable woman, was devoted to Vincent. Fiercely independent and private, she abhorred what she viewed as intrusive attempts by Social Services to insinuate themselves into her affairs. She’d found her early experiences with such services demeaning and frustrating. Long ago, she and her husband, Gregory, had bravely rejected professional advice to institutionalize their son. They took loving—sometimes imperfect—care of Vincent for the rest of their lives.

We, in contrast, silently feared the eventual responsibility for Vincent’s care. How would he deal with our two young daughters, and they with him? We feared the financial and logistical ramifications of bringing him into our home. Janice refused to discuss his future with us. Disagreements about Vincent, physical distance, and her flagging energy made serious conversation difficult. We offered to

Veronica Pollack (pollackv@comcast.net) trained as a pediatric clinical nurse specialist and taught graduate nursing at the University of Rochester (New York) and Yale University. Harold Pollack (haroldp@uchicago.edu) is associate professor of social service administration and faculty chair at the Center for Health Administration Studies, University of Chicago. [Health Affairs 25, no. 1 (2006): 231–236]
move them near us. She was touched but never quite ready.

Veronica, who is four years older than Vincent, had helped care for him while he was growing up. Yet we no longer knew him well. We saw him only at holidays and on visits. Even then, he spent much of his time alone in his room or sitting passively watching television.

Food provided his main gratification. Whenever he was hungry, he would go to the refrigerator, fix a bulging peanut butter sandwich, and drink it with a brimming glass of Pepsi. Five feet eight and one-half inches tall, Vincent weighed perhaps 340 pounds at the time of Janice’s death.

He often soiled his clothes and linens, sometimes furniture too. Laundry and housekeeping were constant challenges. He didn’t sleep well. At night he would blare his TV, scavenge in the kitchen, and tear up books and old photos. Having limited tools to negotiate conflict, Vincent would bite his palms when he was angry or frustrated. He sometimes hit or pinched Janice, leaving small bruises.

A New Life Begins

After Janice’s funeral we helped Vincent pack for the 750-mile drive to our Illinois home. Contemplating this new chapter in our lives, we noted many advantages we enjoyed. Veronica had trained as a pediatric clinical nurse specialist. She’d taught graduate nursing, had recently completed her doctoral coursework, and was starting her dissertation. Harold is a tenured professor of health policy.

We quickly found that many of our fears proved worse in prospect than in the reality of Vincent’s care. We’d underestimated Vincent in many ways. He has an IQ in the mid-fifties and struggles to communicate verbally. Yet he understands everything we say. He has an uncanny memory for things meaningful to him: television characters, our friends, and the household schedule.

From the moment Vincent arrived, he worked hard at keeping clean. He proved polite and appropriate in social settings. He adored his nieces, becoming a fixture at their games and concerts. Hannah (age seven), then more gradually Rebecca (age nine), came to enjoy him, too. They began to feel protective, eagerly helping when tasks became frustrating or complicated for him. Vincent and Hannah became TV buddies, watching the Food Network and ESPN. Rebecca enjoyed serving Vincent meals and making silly faces that made him laugh.

Vincent accepted, with some grumbling, drastic life changes. His room has no TV. He ate the portion-control diet we served him. By fall 2004 a handsome, slimmer man emerged; he now weighs 175 pounds. He has come to enjoy chaperoned
visits sponsored by local special recreation agencies to the Hard Rock Café, lunch cruises, bowling, aerobics, casinos, art class, and the track. He shops weekly at Target to augment his collection of necklaces, wallets, key chains, bracelets, and pouches. He calls Harold’s parents Grandma and Grandpa.

**Entering A New Health Care System**

**Arriving back home in Illinois,** we arranged for Vincent’s first teeth cleaning in years. Before the appointment, our girls read him a picture book about dental checkups. He was cooperative and unafraid when the dentist donned her mask. “Like Hannah said,” he reported with a smile. The dentist scraped off layers of plaque. No cavities.

We worried more about other matters. Janice had long refused most medical interventions—for herself and for Vincent. We never really learned why. To our knowledge, Vincent hadn’t seen a doctor in years. A colleague referred us to a kind internist who serves adults with developmental disabilities. Vincent submitted good-naturedly to many tests. When a nurse’s aide demonstrated using a thermometer by placing it under her tongue, he giggled uncontrollably, leading both to collapse with laughter.

His doctor presented an inventory of hitherto undiagnosed ailments: venous insufficiency leading to cellulitis of the lower legs, fungal infection, sleep apnea. His cardiovascular health proved surprisingly good, although we’ve since encountered a still-undefined clotting abnormality that remains a concern.

An ultrasound revealed deep-vein thrombosis in Vincent’s left leg, and he was hospitalized. When he was able to leave the hospital, we were told that he needed to continue his Lovenox anticoagulation treatment, injected twice a day in the abdomen. The cost was $80 a shot, and Vincent’s Illinois Medicaid enrollment was still in process. Told that he would still need at least two weeks’ worth of Lovenox, we went to a pharmacy, put $1,100 on our Visa card, and went home.

Fortunately, Vincent needed only five days of Lovenox—leaving us with $560 in unused medication. Veronica called the pharmacy about returning the factory-sealed packets for a refund. No, that would be unlawful. We were, however, invited to donate it for charitable distribution. Two months later we received a generic Social Security mailing about a Medicare drug discount card. This sent us to a Web site that detailed the Illinois Pharmaceutical Assistance Program (IPAP). It would have covered Vincent’s Lovenox. We had encountered many professionals who might have referred us to IPAP but hadn’t. We hadn’t done our homework, either.

The Lovenox saga reached an untidy but remunerative ending. We received notice that Vincent might be eligible for retrospective reimbursement. A brusque Illinois Department of Health Services worker offered three contradictory explanations of why we wouldn’t see a cent of “drug-store expenses.” Veronica nonetheless called the pharmacy. Within minutes we got the $1,100 back.
Finding Services

Vincent receives social security survivor benefits (and thus Medicare) as a disabled adult child based on his father's earnings. The day after Janice's funeral, we went to the local Social Security office, and, after a short conversation, Veronica was appointed representative payee, making her responsible for administering Vincent's benefits. The administrator asked whether Vincent understood that the benefits were for him rather than for us. Vincent smiled, scrawled some letters around the dotted line, and we moved on.

Medicaid was another matter. Vincent had received New York Medicaid, but this meant nothing in Illinois. “Get him on Medicaid” became a refrain, the first and often only recommendation we received. We pursued Illinois Medicaid enrollment from the moment Vincent arrived.

Vincent missed his old ARC workshop, where he did limited piecework and hung out with friends and staff. He crayoned dozens of pictures labeled “ARC” in case we missed the point. We approached the local agency identified as our gateway to services. Staff there informed us that we first needed to secure Medicaid. Moreover, they said, “Assistance with Medicaid is not our role. Perhaps you should hire a lawyer.” They guessed that enrolling him would take months. Once Medicaid was secured, they told us, they could begin to search for a workshop placement. We were then advised of the long waiting lists.

Discouraged by the prospect of months without services, Veronica found an Internet workshop list and hit the phones. After a day of questions and begging, she found a workshop that would take Vincent immediately. It could also help, if necessary, with Medicaid enrollment. Vincent's caseworker was not pleased that we had found the placement ourselves.

A few months later we received form letters from the state announcing Vincent's Medicaid enrollment. The jargon-riddled computer printouts were virtually incomprehensible. Eligibility is verified monthly, and Vincent is always deemed eligible. Yet the baffling mechanics produce many errors and delays, making caregiving more difficult and wearing than it has to be.

From one perspective, Vincent is a pauper: He earns five dollars a week packing dog bones into bags. Yet he enjoys the middle-class comforts of our home. We have met other professionals caring for a sibling or adult child with disabilities. Virtually all receive Medicaid. Medicaid is the dominant, often the only, source of payment for key services. Few families, even among the affluent, could provide decent care without it.

So families do everything they legally can to maintain Medicaid eligibility. Recognizing this reality, states establish (or tolerate) diverse asset-shielding arrangements. Many families still devise backhanded arrangements that preserve Medicaid eligibility while creating unforeseen dangers and problems. Some parents nominally disinherit a disabled child, leaving funds to an able-bodied sibling.
honor-bound to help. These arrangements have no legal force, and their furtiveness discourages planning. What if the sibling dies? What if she borrows from those funds? Even when such arrangements work as hoped, they lead families to waste time and money structuring transactions to preserve Medicaid entitlements.

This is not the place to consider the proper balance between compassion, target efficiency, and cost control in means-tested aid. We believe, however, that current policies impose large, often-hidden burdens out of proportion to the modest accompanying savings of public money.

**The Quality Of Interventions**

Vincent joined us during a crisis. He and we were grieving Janice’s death; we were settling her affairs, and Vincent was moving far from the only life he had known. One might hope that public programs would bring continuity and support in such a time. Almost the opposite occurred. No one called to ask how Vincent was doing. No one checked to see whether we were treating him well. Social Security checks flowed, and Vincent’s Medicare payments continued. Every other service and entitlement was severed with his move.

Social Services might also have helped before things reached that point. Janice was a sixty-eight-year-old widowed smoker. As far as we know, no one asked Janice what would happen to Vincent if she could no longer care for him, let alone about touchier matters, such as when he had last seen a doctor.

Two million adults receive aid through representative payees. Surprisingly few studies explore such arrangements. Many payees are from the now-elderly pioneering generation that cared for disabled children at home. These children are reaching middle age. Their parents received critical (but incomplete) public supports that made home care feasible but failed to nurture alternatives when this no longer works. Some families navigate successfully without help. Others, like ours, limp along until crisis intrudes.

Common delays and frustration of academic medical care make caregiving more wearing than it has to be. Bureaucratic mess-ups happen often, and they are maddeningly intractable. Hospital professionals who cringe at minor medication errors seem strangely complacent about equally burdensome billing errors.

Medicaid has been generous to us, sometimes surprisingly so, covering services such as occupational therapy scarcely imagined thirty years ago. Medicaid’s administrative incapacities remain palpable. Provider coordination is spotty, causing needless confusion and acrimony. Telephone help lines go unanswered or feature embarrassingly outdated recordings. Help line operators are often uninformed and unhelpful. One person important to us never returned a single call. We sometimes give up calling and go directly to the Medicaid offices. Veronica, her professional life on hold as she provides Vincent’s care, waits for hours. She stares at a
happy-talk poster: “Work makes sense.”

If we are sometimes treated shabbily or incompetently, it can hardly be otherwise when staff members are overburdened, poorly trained, and poorly supported and when legislators fail to provide resources to implement programs well. We do not expect perfect providers; we make many mistakes ourselves. We do expect respectful partners who work to understand and address our long-term concerns.

The Coming Years

Our life with Vincent has gone more smoothly than we had any right to expect. It works because our family circumstances allow it and because Vincent summoned remarkable and unexpected resilience. Yet we have just begun. The relentlessness of the task remains daunting. Vincent has had multiple hospitalizations and has other important medical needs. At one point, he needed four weeks of round-the-clock home IV care. We spent ten hours in the emergency department after he pried off a child lock and ate a box of chocolate-flavored vitamin chews. Loneliness, boredom, and resentment creep in when our household grinds to a halt after Vincent loses a toy, when he pinches Harold in frustration, when we again must rush a child's bedtime story. Just as Veronica did thirty years before, the girls worry that Vincent will embarrass them with their friends. He wanders our hallways at night, so we must lock the refrigerator and the cabinets. We ourselves are often awake, washing mountains of soiled laundry. Vincent wants to move into a group home. He loves us, but he prefers his peers. We want this, too.

In the meanwhile, Vincent is talking more. Fascinated by e-mail, he dictates a story for relatives:

I go to college and live in the K-house with K-brothers Mike and Keith. I have a roommate Steve. We play pool in our shorts. I win, and he buys me ice cream. I play football. I have new parents, Mr. and Mrs. Walsh. I call them Mom and Dad. Mom takes me shopping. She buys me a cell phone, necklaces, shirts, and a car. I have a girlfriend Celeste, played by Cousin Laura. We get married. We have two children.

He wants, simply, to be a man. He knows well enough that his mind denies him these possibilities. He still wants to experience what life has to offer. We can help him do this. We owe him that.

This is no easy task. We spent years baffled by Janice's estrangement from systems that might have helped. We now appreciate what might have led her to that point. Social Services and medical systems do much to alienate and beleaguer people who need help. In failing to show a human face, these systems encourage families to turn away, to use services grudgingly, to leave problems unaddressed. These systems devote much time, attention, and resources to their internal priorities and to mechanics of eligibility and reimbursement. There is too little left for the smiling man who likes necklaces and ice cream, and who needs help.