

# Activities Of Daily Living

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I stood inside the entrance of Central State Hospital in Indianapolis, Indiana, waiting to get patted down. It was my first visit to the institution, in 1992. I was twenty-four and had been working in the field of disability and mental health for two years. The paperwork was mind-numbing, as were the seemingly endless acronyms rattled off during lengthy treatment-team meetings. My official title was “job coach,” and my annual salary was \$13,480, less than I had made at the ceiling-tile factory where I’d worked to pay my college tuition and where my dad was still employed.

My position had only recently been created. The Americans with Disabilities Act of 1990 had stipulated that workers with disabilities had to be offered a job coach to assist them in their search for employment. Without such assistance, people with disabilities were often relegated to workshops where it was common — and legal — for them to earn twenty cents an hour or less. In fact, many of the people I tried to help find jobs in the community were instead whisked up and placed in such workshops, sometimes without their consent. I’d seen weekly paychecks that totaled just three dollars for forty hours of work.

The person I’d come to the hospital to see, Riley, was in the process of being transferred out as part of an effort to reduce the number of people in institutions. He was one of hundreds of men and women being “transitioned into the community” — which likely meant being sent to a group home.

The buildings at the hospital sprawled across 150 acres of smooth green turf and sycamore trees. (Most state mental hospitals I visited had gorgeous campuses that belied the grimy stairwells and darkened restraint rooms behind their walls.) I was aware of the irony of my situation: I, who regularly thought of quitting my job; who could barely get to work on time or comprehend the massive paperwork; who was struggling to leave behind the alcohol and drug habits that had gotten me through my shifts at the ceiling-tile factory — I was being paid to help someone else find rewarding work. It was one of many such hypocrisies in the system: Overweight case managers reported that obese clients needed behavior plans to address their eating. A residential director who often invited colleagues to take a dip in his hot tub expressed grave concerns about how his “retarded” male clients ogled female staffers. A man with bad breath and body odor shamed people with disabilities for having poor hygiene.

The woman frisking me wore a name tag that read SUPERVISOR III. She waved a metal-detector wand over me while chatting with a co-worker about recipes.

After scouring the contents of my book bag, Supervisor III said, “You with that program then?”

I nodded.

She seemed to pity me. “All you’re gonna do is rile them up.” She handed me my keys without meeting my eye.

**I feared** she might be right. The first in my family to attend college, I was out of my element in human services and felt more than a little like a phony. I’d grown up on farms and held only factory, fast-food, and cleaning jobs before this one. There was both disability and mental illness in my family, plus addiction, and we’d lived on the brink of poverty most of our lives. I’d taken this job hoping to use my degree, but I was afraid I didn’t have what it took to be valued for my mind and not my strong back. Most of all I worried I’d have to return to the factory in Lagro, Indiana, and become a “lifer” — the term the union men used for a foolish fellow who’d spent money on a college degree and ended up working there anyway, too scared to leave.

The truth is, I’d had a difficult time letting go of the factory. I often drove more than two hours on the weekends — and some weeknights, too — just to sit with my dad and the union men, eat sandwiches, and smoke. Some nights we’d leave the factory at midnight and drive to the Hoosier Point for a pancake “breakfast.” Afterward I’d stand in the parking lot with my dad and the other men, feeling anxious and barely able to breathe. I wanted to stay with them, roll up my sleeves, and let sweat and physical effort rule.

**After walking** what seemed like a mile in a fog of bleach and Pine-Sol, I finally approached room 203. Riley was one of the last on his wing to go. From his chart, which I’d been handed the Friday before, I knew he was ten years older than I was, less than five feet tall, and that he had been labeled with numerous deficits and problems. I half expected him to be unresponsive and living in squalor, but he sat on his neatly made twin bed, reading an issue of *Prairie Farmer*. When he saw me in the doorway, he smiled a gaptoothed grin, stood up, and placed the magazine on an end table beside a neatly arranged Bible, yellow comb, and container of talcum powder. The cinder-block room also held a small

writing desk, a single folding chair, and, for reasons I never did find out, a large oil drum lined with a trash bag. On a solitary shelf above the bed gleamed a plastic Polaroid Sun 600 instant camera and a brown leather carrying case, obviously oiled with care. It was hard to imagine that Riley had lived there for twenty years. I thought of my own apartment, where the bed was unmade, the sheets unwashed, the floor strewn with clothes. I was behind on the utilities and the rent and often drank too many Busch Lights before bed. My days started with black coffee, Tylenol, and sometimes a joint, and they ended with visions of failure: an image of me, gray haired and bent over, at my union retirement party, a bronze ceiling tile my reward for fifty years at the factory.

Riley bowed slightly to me and extended his hand. He wore corduroys, a thin sweater, white socks, and brown penny loafers with nickels under the straps. His chart said he'd been abandoned by his parents some twenty years earlier and didn't speak. "Deaf and dumb" was how the paperwork put it. It also said he was "easily agitated, prone to fits, stubbornly defiant."

"My name is Doug," I said. "I'm your job coach."

Riley's dark eyes examined my face closely, as if he might be trying to remember me from somewhere. Then he sat back down on the bed and picked at his cuticles as I pulled up the folding chair and fumbled with my paperwork. I'd been told there was to be a treatment-team meeting where I'd be filled in on Riley's case, but by the looks of things, it would be just Riley and me. Canceling meetings with no warning was so commonplace in the human-service field it had its own acronym: USWN, for "unscheduled without notice."

As I arranged my forms, Riley didn't appear defiant or unruly — more like shyly eager. I clicked my pen and read the first question: "What do you like to do with your spare time?" Too late, I recalled that Riley couldn't hear. He stared intently at my face. "Sorry," I said, and Riley waved my apology off as if he'd heard it. I apologized again, and he shook his head as if to say it was nothing to worry over. It dawned on me that he was reading my lips. I asked if that was what he was doing, exaggerating my words the way people do who don't know any better, and he nodded and smiled, exposing gums where teeth had been. "But that's not in your chart," I said. I rifled through the intake forms and handwritten notes going back two years. Riley began to look bored. I excused myself and left.

At an oval island desk in what once must have been a busy central area, I found a lone woman shoving paperwork into boxes labeled STORAGE. I asked if she knew

Riley and explained that I was there to help him find a job. She wished me luck, saying Riley never wanted to do his chores.

I asked if he read lips, and she replied, "Not that I know of, no. But he understands just fine; don't let him fool you."

The woman turned to answer the phone, and I hurried back to Riley's room, where he was fiddling with the camera. He offered it to me, and I looked it over. "Very nice," I said, handing it back. "Do you like photography?"

Riley passed me the camera again. "Do you want me to have it?" I asked.

He grabbed it and furrowed his brow. He was trying to communicate something, but I wasn't getting it. He stomped his foot. This was closer to how he'd been characterized in his chart. Finally he reached for my hand and placed my fingertips where the film was inserted, examining my face as if to see if I was really as slow as I seemed.

"Film?"

Riley nodded his head with such force I could hear his vertebrae pop. Then he opened the single drawer of the writing desk and extracted a stack of Polaroids. We sat on the bed together and went through them. There must've been a hundred or more pictures: of the staff, of the institutional grounds, of the cafeteria, of the doctors and nurses, their white coats turning ocher on the aging photos. Some of the Polaroids near the end clearly dated from the 1970s and showed people in bell-bottoms with long, straight hair and wide shirt collars.

He carefully placed the photos back into the drawer and began moving his lips, making sounds that reminded me of mourning doves. An almost unintelligible word emerged. I thought it might be *Sad*.

The rest of the afternoon I followed Riley around the state hospital. Other than the woman I'd talked to at the desk, there was only a handful of staff left on his wing. We passed bulletin boards that held everything from current news clippings to yellowing mimeographed memos. Riley would stop and examine each board. At dinnertime we entered a nearly silent cafeteria, where we ate chipped beef over toast with green beans and fruit cocktail. I hadn't drunk milk from a tiny carton since grade school.

When I returned with Riley to his lonely wing, a new woman was at the island desk. “Hold on,” she said when she saw me. “Where’s your visitor’s pass?”

“I didn’t get one,” I replied, looking around as if someone might appear with one for me. “I signed in, though.”

The woman insisted I wasn’t allowed on the ward without a pass, and she took Riley’s arm and marched him to his room. The setting sun shone through the windows as they disappeared. I stood there for a while, not wanting to go home to my unkempt apartment.

That night, rather than lie in bed drunk and wonder if I’d made a mistake in getting a degree, I drove to the factory, where I sat in the warehouse office with my dad, smoking and drinking coffee as the other union men trailed in. We talked about the production line, contract negotiations, and the inevitable prospect of everyone’s jobs heading to China. A portion of the production line had already been methodically deconstructed, packed up, and shipped to Beijing. The conversation waned, and someone asked me to help shovel coke and sand into the furnace and load a skid with boxes of tile. The physical effort soothed my nerves like a pill. Dad watched me work with an air of disappointment, as though I were committing a petty crime. Near the end of my visit he said to me, “I hope to hell you’re not thinking about coming back here.”

I knew he was concerned about my future, but I heard this as, *You don’t belong here*. I couldn’t escape the feeling that, by going to college, I’d betrayed my family and implied that their fast-food or factory or farming jobs weren’t good enough. “I’m just helping out,” I told my dad, my face hot. He forced a smile and attempted to pat my shoulder, but I turned and followed two union men into the parking lot for a beer.

**I returned** to Central State Hospital two days later. Riley was in his room, polishing the camera’s lens with a sock. I sat down next to him on his sagging bed and touched his arm. He stopped what he was doing and stared at my mouth. “I’m not sure I can help you,” I said.

Riley went back to cleaning the camera. He was fastidious, smelling faintly of bleach, his brown hair cut short and combed so purposefully that the lines reminded me of a newly plowed field. He stood and placed the camera carefully on the shelf, then picked up a shaving kit and motioned for me to follow him.

In the institutional bathroom was a long row of porcelain sinks. Riley unzipped the kit and arranged the razor, shaving cream, and aftershave bottle in precise positions on one sink. He patted his face. I noticed the stubble there.

“You want me to shave you?” I asked.

He beamed and went to a closet to fetch a folding chair. Easing into the seat, he said with great effort, “Save.” Then he added, “Pease.” Riley closed his eyes and laid his head back, exposing his squat neck to me, a near stranger. I ran hot water until the steam rose and swiped the razor under the tap. Then I squirted a ball of foam into my hand and worked it along his cheeks and down his neck. He giggled when I applied it under his nose. I was nervous to use the straight razor on Riley — I’d used only disposables on my own face — but once I realized I wasn’t going to cut him, the task became meditative, almost calming. I left the space under his nose for last. I tapped Riley on the shoulder and made a face, showing him how to tuck his lips in, make the mustache area flat. He gave a hoarse, nearly silent laugh, then sat back and performed the face I’d shown him. I carefully shaved the pale skin of his upper lip.

Afterward we walked the hospital grounds. I was beginning to understand Riley better: the way he pointed, nodded, cut his eyes to the side. His own words wore him out, but he seemed to like it when I talked. We passed a fenced-off pond and climbed a green hill dotted with sycamore saplings like candles on a cake.

“What about a job working with cameras?” I asked.

Riley nodded and pretended he was taking pictures.

“I’ll see what I can find,” I told him. The sun was starting to set, the light turning golden. Riley’s digital wristwatch chimed, and he shut off the alarm and started toward the cafeteria. I followed, unable to recall the last time I’d eaten.

The following Monday I signed Riley out, and we hit the road. He was so short that the bucket seat of my ratty Caprice swallowed him up. He held his Polaroid Sun 600 in his lap as if it were a religious relic.

Our first stop was a pharmacy. Riley knew where the right film would be. He approached the glass case and peered in, making soft cooing sounds. I asked the woman behind the counter for ten packs of instant color film, enough to take eighty photos. As she started stacking them on the counter, Riley shuffled his feet and laughed. Afterward we got burgers, shakes, and fries at a drive-through, and I drove to a park. Riley tore into his food with so much gusto he left a ring of ketchup around his mouth. When I helped clean his face, the napkin tickled his nose. Riley gave me an intense look, his eyes watery, and he struggled to say, "Fiend."

"You're my friend, too, Riley," I said.

He nodded as if satisfied and patted my hand. Then he got out of the car with his camera and a pack of film. At a picnic table Riley ripped open the pack and expertly fitted the film into place. He sat for a moment, looking down at the camera in his lap. He'd had it a long time and had used it to capture images of the people who had come in and out of his life.

Riley took just three carefully chosen pictures that day: a sycamore tree with a crow perched on a limb; a man with a long beard sitting on a bench; and two white poodles who looked exactly alike. After a few hours my beeper started trilling — no doubt someone at the institution had complained that we'd been gone too long. In the car Riley kept arranging the three Polaroids along his thigh, touching their edges lightly, making imperceptible adjustments. I stopped at a Dairy Queen and bought him a vanilla cone on the way back.

On the hospital's front steps we were greeted by a staff member with a goatee and kind eyes who put his arm around Riley and asked if he'd seen any pretty ladies. The man introduced himself as Sid. Riley handed me the camera, and I snapped a picture of the two of them. After it had developed, Sid pointed to Riley's image and asked who that handsome devil was. Then the two of them started using sign language.

"I didn't know Riley signed," I said.



Sid explained that neither of them was fluent; it was a little American Sign Language mixed with gestures they'd devised.

That's when I recognized Sid from the Polaroids in Riley's desk drawer. He was the man in the denim shirt with the black hair past his shoulders — only now it was short and graying.

As I turned to leave, Riley hugged me from behind, his arms around my waist, head pressed against the middle of my back.

**O**n my next trip to the factory, after the others had fired up their trucks and slowly exited the parking lot, Dad got a squeegee and Windex and started to clean the windows of my car. He said they were so dirty, he didn't understand how I could see out of the goddamn things. After he'd finished, he adjusted his cap, lit a Salem, and exhaled smoke. I'd seen this expression on his face before: he was trying to get the words to come. Crickets chirruped, the power station hummed, and light flickered from the dock doors.

After a long moment Dad said, "I like the visits, Son. . . ." He looked away toward the dark road in front of the factory. My throat ached as if I'd swallowed a golf ball. "You got a lot of work there in Indianapolis," Dad said. "You should try hard. Don't think it'll come easy." I think he knew I was stuck between the working life I'd always known and one I still didn't understand. I took a step toward him, hoping for a quick embrace, but he got in his truck and started the engine. "Be careful on the bypass," he said. I thought I'd heard a quaver in his voice, but I couldn't be certain. I watched as he turned onto the road and disappeared.

I cried most of the way back to my empty apartment. Then I drank too much while trying to type a résumé for Riley on my electric typewriter. By morning I'd slept only a couple of hours, and I rushed to make copies at the Kinko's down the street.

**I** had work to do, helping other people find jobs, but I picked up Riley every other day because I wanted to get to know him better. We had a beer at a pub in

Broad Ripple, a village north of downtown. We played putt-putt golf. We jogged in Eagle Creek Park. (Riley wasn't fast, but he loved the running shoes I'd bought him — size 6 from the boys' department.) We took tours of my friends' workplaces: one worked for a vet; another operated a carpet-cleaning business. We visited the fire station, the library, the fairgrounds, the zoo, the university campuses. We volunteered at a shelter, where Riley took Polaroids of people as they received their paper plates of white bread and meatloaf. He gave them the photos to keep.

On days when I didn't visit, I missed Riley. At night, when I felt tempted to smoke weed and drink beer, I pictured him lying alone in his dormitory room, the Polaroid camera on the shelf above him, the nearly abandoned wing deathly quiet. I was trying hard to find him a job, but all the fast-food places weren't interested in hiring someone who didn't speak or hear. I stayed up late paging through classified ads and picking up my apartment. I cleaned the tub, vacuumed, and put away laundry. I called my dad at the warehouse to talk about the union negotiations, and he seemed relieved that I was phoning him from Indianapolis and not coming to see him in person. In the morning I went to the labor office and copied job listings. Most were for landscaping, construction, and telemarketing, but one stood out: Robert's Camera Shop needed a salesperson. I knew Riley wouldn't be a good fit — he couldn't talk to customers — but maybe he could clean up or do something in the storeroom. I made an appointment with a manager, telling him I was interested in the position myself.

The next day I went to the meeting and explained my real purpose. It was an awkward part of my job: How much should I reveal up front? The manager agreed to meet Riley, and I rushed to the state hospital. On the way I made a list in my head of what Riley would need: a jacket, a necktie, some cologne. My head was clear now that I didn't drink myself to sleep every night, and I felt better than I had in months. Surprising what ten days of sobriety can do.

In the hospital lot I saw news vans parked along the sidewalk and a fleet of vehicles with government tags. Two more news vans arrived, their back doors opening before they even came to a full stop.

I got out of my car and headed for the front entrance of Riley's building, but a security guard blocked my path. "Not today," he said.

I asked what was going on.

“We’re on lockdown,” he said.

“Why?” I asked, worried about Riley, but the security guard just went back inside and locked the door. On the steps where I’d taken Sid and Riley’s picture, a podium had been erected, and folding chairs were arranged at the bottom for the media. My pager was going off over and over: my boss, my co-workers, and other numbers I didn’t recognize. I waited around rather than drive back to the office, trying to remember where Riley’s room was as I peered up at the third floor.

After an hour or more the hospital administrator and the governor’s public-relations staff read prepared statements. Apparently someone had died overnight: a woman had been found drowned in a bathtub. The administrator announced that he and his staff would cooperate fully with the governor’s office to determine what had gone wrong. Then the press conference was over.

I made one last attempt to get inside, but the door was still locked. A placard on the window said the hospital would resume normal visiting hours once the situation had been resolved. I walked back to my car, looking over my shoulder as if hoping to see Riley exiting the front doors with Sid and his camera. I stayed in the parking lot until most of the other vehicles had left. By then my beeper had gone dead.

That night at my apartment I watched the news. There was talk of a grand-jury investigation surrounding the bathtub drowning, and also another case in which a person had frozen to death in bed because a window had been left open. Over the next month more charges of abuse and neglect emerged. There were plans to close the hospital completely. My every attempt at visiting Riley was thwarted. I was no longer on the list, and getting back on it seemed impossible. Where once there’d been a paucity of staff, now the place seemed overrun by professionals.

Weeks went by, and I worked on the rest of my caseload. Sitting at my desk one afternoon, I opened a letter that said Riley would no longer need my services: he’d been admitted to a workshop program up north, on the Illinois border. The memo listed the reason for Riley’s move as “IS-ADLs for employment.” I went in search of someone to explain the acronym and learned that it stood for “insufficient activities of daily living.” I thought of Riley’s neatly made bed, and how he’d taught himself lip reading and some sign language. I thought of how he’d survived for decades in the institution — something I did not think I could have done myself.

I called the hospital, pretending I needed Riley to sign a document, but the receptionist told me to put it in the mail. Finally I asked my boss if I could talk to her. She was carrying a load of files, and I followed her into an office lined with filing cabinets.

“I need some help getting to see the guy at Central State,” I said. “They won’t let me in.”

She dropped the stack of files on her desk, sat down, and blew hair out of her eyes. She wished she could help, she said, but because of the investigation, there was nothing she could do. “Try focusing on the other people on your caseload.”

“But I was so close,” I said, about to cry. I told her I couldn’t get his face out of my mind.

My boss handed me a tissue and said, “Look, this work isn’t for everyone.” She told me there was no way to do it well and not let it get to you.

Back at my desk I pictured Riley riding in a van up north, looking out the window at the flat fields going by. I hoped that Sid would get to ride with him and that there’d be a few stops where Riley could take pictures. Later I sent more packs of film to an address I’d tracked down for him, but I never saw Riley again. I still have some of those Polaroids, including a blurry one that Sid took of Riley and me together, sitting on a bench at the hospital. If I focus hard enough on his face, I can almost make out his expression. I want to believe he was happy.