First Person Account: How the First Wave of Deinstitutionalization Saved My Mother From the "Snake Pit"

by S.L. Aldridge

The article that follows is part of the Schizophrenia Bulletin's ongoing First Person Account series. We hope that mental health professionals—the Bulletin's primary audience—will take this opportunity to learn about the issues and difficulties confronted by consumers of mental health care. In addition, we hope that these accounts will give patients and families a better sense of not being alone in confronting the problems that can be anticipated by persons with serious emotional difficulties. We welcome other contributions from patients, ex-patients, or family members. Our major editorial requirement is that such contributions be clearly written and organized, and that a novel or unique aspect of schizophrenia be described, with special emphasis on points that will be important for professionals. Clinicians who see articulate patients with experiences they believe should be shared might encourage these patients to submit their articles to Schizophrenia Bulletin, First Person Accounts, EEI Communications, 66 Canal Center Plaza, Suite 200, Alexandria, VA 22314.—The Editors.

Something went wrong with my mother in her late teens, I was once told; she seemed fine to me when I was a small child and she was in her forties. Once, she chased me around our walnut grove in the San Fernando Valley (where I'd mischievously turned on all the in-ground sprinklers), gave me a time-out, and then made up with me over a platter of steaming-hot French toast swimming in maple syrup. She was Mommy, and I loved her. I didn't meet another child until I was 6, starting first grade; we were all each other needed.

When I was an infant, my mother divorced my father—whom she described as a wife-battering alcoholic—and remarried. She, my stepfather, and I moved to a large, comfortable home in Santa Monica bought and furnished by my grandmother (who had long been desperately worried about her last surviving child). Thanks to Grammy's foresight, we always had food, shelter, spending money, and more—a baby grand piano, fine china, sterling silver, two sets of crystal stemware. Grammy, who lived in nearby Brentwood, mothered me every chance she could. I've always carried her goodness in my heart.

The first change I noticed in Mommy came right after Grammy died, in 1957, when I had just turned 10 and Mommy was 49. One day, standing in the kitchen, I heard Mommy talking to her mother and deceased brothers from the spare bedroom. It gave me the creeps. "Stop it!" I begged. She wouldn't stop. Soon she had persuaded my stepfather to quit his job to stay home and look after her.

She began to fear going out. Daddy would drive us to the grocery store, and he and I would get out of the car, but my mother would say, "I feel faint. You shop. I'll wait here." We'd return with a cart full of groceries to find her huddled on the floor of the backseat of the car, shaking and sobbing. Daddy and I conspired to bring her sweet treats—a lime sherbet cone, Dutch Girl cookies—but she didn't cheer up. He was a simple, kind, depressed man with an eighth-grade education who drank a lot, loved us, and grew more helpless and bewildered as the years rolled by.

Mommy flew into rages. She sat in the breakfast room and stared at traffic for hours at a time, chain-smoking Pall Malls until her fingers turned dark yellow. On good days, she'd turn on the TV and we would sing along with Mitch Miller and gobble up greasy chicken dinners rushed to our door by a man in a yellow car with a plastic chicken on the roof. On very good days I would coax her to the piano where, her long fingernails chattering on the keys, she would play Schumann and Mozart and silly tunes like "Shine, Little Glow-Worm, Glimmer, Glimmer" from the 1920s. I learned to read music sitting beside my mother on the piano bench, matching the notes to the keys and the melody.

Dr. Sable, a genial GP who made house calls, prescribed pills for energy, pills to soothe her nerves, pills to
just a fainting spell. Hands shaking, I dripped ammonia
through barely parted Venetian blinds. He and
snapped, "He claims he's never loved me!" The very next
until her face changed. Slamming down the phone she
mother called Johnny on the phone. I giggled excitedly—
Mrs. B. sat behind a picture window that faced their patio.

One of the play-sick things Mommy did was threaten
suicide. "I'm going to take all my pills, and when I'm
gone you'll regret how mean you were to your poor, sick
mother!" Even at 10 I recognized that as a grown-up
version of a tantrum. But the first time she collapsed in a
heap in front of me I was petrified: as Mommy knew, a
few months earlier Grammy had died of a heart attack
before my eyes, complete with a full-body seizure and
death rattle.

I raced for the medicine cabinet. A great fan of the
Cherry Ames series (the adventures of a young nurse), I
grabbed the spirits of ammonia bottle, praying this was
just a fainting spell. Hands shaking, I dripped ammonia
onto a hankie—oops, some landed in my mother's left
mouth. She leaped to her feet and ran screaming to the bath-
room sink. After that, whenever I found Mommy's lifeless
body draped across a doorway I stepped over it and went
about my business.

Once she told me my tummyache would feel better if
I took one of her pills. Then it was "Oh no! You took it
from that bottle?" She ran with me to my bedroom, flung
me on the bed, and wrapped her arms around me. For an
instant I relaxed and dared to feel safe. But she was sob-
ing "My baby's going to die!" Those words launched me
onto a hankie—oops, some landed in my mother's left
mouth. Dr. Sable assured me the pill

undo the other pills and let her sleep, pills to wake her up.
Daddy and I had high hopes with each new prescription.

But soon Mommy refused to leave the house at all and
would not go to the hospital for tests the doctor recom-

ended. Dr. Sable took us aside. "She plays sick to get
attention. She knows the tests would prove nothing's
wrong with her." Grammy had once told me more or less
the same thing. It did seem to fit.

Years later, when Dr. Sable tried to wean her off the
pills, Mommy flew into a withdrawal panic. Somehow my
stepfather talked pharmacists all over town into giving her
years of "just one more refill" of these dead prescriptions.

Mommy stayed in the house; Daddy went out to
drink and came back to throw up whiskey on the bird-of-
paradise plants by the garage. We begged Mommy to go
to the hospital, but she said people were against her so she

would not go to the hospital for tests the doctor recom-

ended. Dr. Sable took us aside. "She plays sick to get
attention. She knows the tests would prove nothing's
wrong with her." Grammy had once told me more or less
the same thing. It did seem to fit.

Years later, when Dr. Sable tried to wean her off the
pills, Mommy flew into a withdrawal panic. Somehow my
stepfather talked pharmacists all over town into giving her
years of "just one more refill" of these dead prescriptions.

One of the play-sick things Mommy did was threaten
suicide. "I'm going to take all my pills, and when I'm
gone you'll regret how mean you were to your poor, sick
mother!" Even at 10 I recognized that as a grown-up
version of a tantrum. But the first time she collapsed in a
heap in front of me I was petrified: as Mommy knew, a
few months earlier Grammy had died of a heart attack
before my eyes, complete with a full-body seizure and
death rattle.

I raced for the medicine cabinet. A great fan of the
Cherry Ames series (the adventures of a young nurse), I
grabbed the spirits of ammonia bottle, praying this was
just a fainting spell. Hands shaking, I dripped ammonia
onto a hankie—oops, some landed in my mother's left
mouth. She leaped to her feet and ran screaming to the bath-
room sink. After that, whenever I found Mommy's lifeless
body draped across a doorway I stepped over it and went
about my business.

Once she told me my tummyache would feel better if
I took one of her pills. Then it was "Oh no! You took it
from that bottle?" She ran with me to my bedroom, flung
me on the bed, and wrapped her arms around me. For an
instant I relaxed and dared to feel safe. But she was sob-
ing "My baby's going to die!" Those words launched me
onto a hankie—oops, some landed in my mother's left
mouth. Dr. Sable assured me the pill

Mommy was always frightened. I felt sorry for her,
but things she did to soothe herself terrified me. Late at
night she held long conversations with imaginary people,
yelling down the dark hall between our bedrooms that I
must chime in. If I didn't, she'd scream, "Well, I guess
nobody cares about me, do they, Grammy? Nobody cares
that my feet hurt and my back's broken." My line was a
shouted "I care, Mommy, I care a lot."

Once, very slowly and silently, I dared to shut my
bedroom door. I crept back to bed, covered my head with
pillows, and began to hum with my fingers in my ears.
Just as I drifted off she came flying down the hall,
slammed open the door, and tore off my covers, shrieking,
"Don't you dare ignore your mother!"

Years went by. Now and then my biological father
would drop by for a visit and take advantage of my fam-
ily's disarray to molest me. I started high school, but my
parents never let me graduate to calling them Mom and
Dad. I figured I wasn't really supposed to grow up. Later,
though, I knew they were the ones with cruelly stunted
growth.

Though we had money to fix it, our lovely house
sagged on its termite-chewed foundation and no door
could close even had it been allowed to: Mommy couldn't
leave, so we couldn't fumigate. The dishwasher and wash-
ing machine broke and were not repaired. First the on-off
light for the furnace burned out, so it was hard to know if
the furnace had power and should be running, or was
switched off; then the furnace itself broke, so the light no
longer mattered. I couldn't invite friends home, but I had
none to invite anyway. The social skills other kids learned
from their own families were something I picked up from
books, TV, and furtive observations of happy families,
and tried out like a method actress the rare times I got a
chance.

Mommy stayed in the house; Daddy went out to
drink and came back to throw up whiskey on the bird-of-
paradise plants by the garage. We begged Mommy to go
to the hospital, but she said people were against her so she
couldn't leave the house. Daddy had long ago taken over
the cooking and housework; I took over much of my
mother's personal care.

I trimmed the mats out of her hair and brushed it
patiently, despite her whimpers that I was tugging too
hard. I tried to coax her into the bathtub at least weekly,
armed with scented soaps, bubble baths, and soothing

Downloaded from https://academic.oup.com/schizophreniabulletin/article-abstract/26/4/933/1923596 by guest on 01 January 2019
oils. Her yellow fingernails curled, and so did her toenails—I insisted on cutting them. But I couldn’t help her poor teeth, which turned green and gray and broke off one by one. She sobbed incoherently, “I don’t have a spine!” She scribbled notes on the backs of unpaid bills and left them around the house: “Get me a real doctor, not that quack!” “Nobody cares about my feet!”

In 12th grade, my advanced placement biology class took a field trip to the state hospital. I rode home on clouds of hope. “There’s a hospital for people like her!?” I excitedly told Daddy. He wasn’t so sure; his drinking buddies had told him her symptoms were typical of menopause. But I convinced him to help me persuade Dr. Sable to commit her.

The doctor sat us down and patiently explained, “You didn’t see what the state hospital is really like, deep inside. You can’t want to send your own mother there. It’s a snake pit. We’re trying to shut them all down.” He looked straight at me: “Families should care for their own.” I felt like a criminal.

Mommy became incontinent of bowel and bladder. Daddy and I changed the sheets four or five times a day. Her hair was like straw, her belly was bloated, and she hardly ate. Once when she struck out at me and I grabbed her arm, my touch broke her skin, drew blood.

Dr. Sable prescribed chlorpromazine, a wonder drug he said could cure her if she’d bother to take it. Mommy hated its side effects and would scuttle under her bed to hide as we approached with bottle and spoon. Daddy or I would drag her out, flip her onto her back, straddle her belly, and force that Thorazine down her throat. When Dr. Sable realized she wasn’t agreeing to take her medicine, he said “That’s it!” and refused to treat her ever again. Every new doctor she called dropped her once they’d spoken with him.

Several months later I learned that if I had let too much of my weight ride on my mother’s abdomen during force-feeding, her stomach would have ripped apart, killing her. I had flashbacks of that scene for years, though it hadn’t happened.

I turned 18 and started sophomore year at a New England college I’d selected for its distance from Santa Monica. One day Mommy phoned in a panic: “Daddy jumped off the cliff! He walked right down to Ocean Park and jumped off the cliff! How could he do that to me?”

I flew home and took a taxi straight to the hospital. Daddy was not dead but blind in one eye, paralyzed on one side, and unable to speak, free of responsibility for my mother at last.

Back home, Mommy was certain that I would now quit college and devote myself to her care. I stood in the den doorway and looked at her. Filthy, frail, and skeletal, dressed only in a white slip and white socks, she weighed less than 90 pounds (though her belly was grossly distended) and lacked strength to do anything but stare into space and chain-smoke. She was dying. The top of my head went prickly and cold; I thought I might faint. I had no idea in the world how to help her. I could barely even wash the dishes; an accident at college had just put my right arm in a cast.

Holding the door frame with my good hand to steady myself, I tried to project love and nurturance into the wood so some might reflect back on me and give me courage. “Mommy, you’re very sick. You might even die. Please let me take you to the hospital.”

She grimaced and shook her head like a child.

“Then I’m going back to Vermont,” I told her firmly. But before I could go, fate stepped in. Aunt Moxie, my mother’s widowed sister-in-law and our only living relative, had wandered with Mommy long-distance for decades. Desperate, my mother phoned her to complain about her ungrateful daughter. Moxie visited one day, in her vast flowery muumuu and mint stole, and called a lawyer the next. Near the end of the week some policemen and two men in white straitjacketed my mother, dragged her into an ambulance, and took her to the state hospital at Camarillo. I flew back East and started writing term papers.

Moxie sent me the medical examiners’ report: “The pt. shows evidence of malnutrition.” They diagnosed a pyloric valve blockage: she hadn’t absorbed any food or much liquid for weeks. Her mental condition was termed involutional psychosis and psychoneurosis (“borderline” neurosis/psychosis). They wrote, “Mrs. Aldridge has been unable to get along with people, stays in her home, says she has no family, but admits she has a daughter. Pt. is using denial and evasion, is hostile, uncooperative, and irrational: says her husband can’t talk.”

Mommy had emergency surgery for the pyloric valve blockage and started new medications. Over two or three days, though she was still very confused, she started to become acquainted with who she was, where she was, what had happened, and why. Then, far too frail to recover, she hemorrhaged and died. My biological father (an attorney) immediately became my guardian. Over Christmas vacation he terrorized me, beat me up, tried to rape me, and set a dog on me. Thanks to a trust set up by Grammy and Pops that went into effect at my mother’s death, I was able to escape back to college and begin a safe, productive, and happy life.

Would any medication from the mid-1960s have alleviated enough symptoms so that my mother could have mothered me? Would my stepfather and I have been better off if she’d lived in the state hospital for those last six or eight years? All I know for certain is that saving my mother from hospitalization meant that the snake pit flourished in my childhood home.
I told the dean of women that my mother had died after surgery. If she knew the truth, I reasoned, she might realize how poorly I fit their Villager sweater set and penny loafer mold and kick me out. The college’s closest thing to a counselor was Chaplain Pott, who said, “Yours is the saddest and most wrenching story I’ve ever heard. I have no idea how to help you.” I had signed up for an intellectually demanding major but discovered I could no longer concentrate enough to learn science or math; I switched to American literature, curled up in a ball, and read my way toward graduation.

Gradually, year by year, I recovered, though I will probably always have some physiological symptoms of post-traumatic stress disorder. In graduate school I married my best friend. We moved to the country, found work, and raised two daughters. I patiently searched out and finally found excellent psychotherapy. For more than 25 years Jim and I have created and enjoyed a nurturing family life with the usual range of joys, hassles, and tragedies. Once the girls were nearly grown I plunged into family life with the usual range of joys, hassles, and tragedies. When the state hospitals were left to shrivel and die, community mental health was supposed to flourish in their place. But ours immediately told me Sam didn’t meet the criteria for services! I called again and again, but no one spoke with had any idea just what those criteria might be or who at the agency might possibly know. While I doggedly tried to solve this mystery, Sam had no caseworker. Clearly I couldn’t go back to work or school until I found a placement for her.

I contacted every professional I’d worked with in 3 years of psychiatric inpatient practica, but nobody could figure out why we’d been denied services. To keep Sam busy while I looked at group homes, I finagled 6 weeks of day hospitalization from our HMO, which required us to return to work and school. The magic phrases to hop to the top of group home lists, as I had intuited, were “compliant,” “never aggressive,” “no substance abuse,” and “stable on meds.”

When the state hospitals were left to shrivel and die, community mental health was supposed to flourish in their place. But ours immediately told me Sam didn’t meet the criteria for services! I called again and again, but not one person I spoke with had any idea just what those criteria might be or who at the agency might possibly know. While I doggedly tried to solve this mystery, Sam had no caseworker. Clearly I couldn’t go back to work or school until I found a placement for her.

I contacted every professional I’d worked with in 3 years of psychiatric inpatient practica, but nobody could figure out why we’d been denied services. To keep Sam busy while I looked at group homes, I finagled 6 weeks of day hospitalization from our HMO, which required us to return to work and school. The magic phrases to hop to the top of group home lists, as I had intuited, were “compliant,” “never aggressive,” “no substance abuse,” and “stable on meds.” Presto, in she went. God help the kids who aren’t so agreeable.

I secured vocational rehab and Medicaid for Sam and started the long road toward supplemental security income (SSI). (Last week she got her first SSI rejection letter. I’ve been warned that the standard process is to apply, get rejected, and win on the second or third appeal. It helps them weed out people who are too ill or too lacking in support to see the process through.)

After a month of my pestering, the community mental health center admitted that it had not received Sam’s
inpatient discharge summary. Once the summary was read, the center agreed to let her see one of its therapists. The center’s mission statement, after all, puts just-released psychiatric inpatients as their top priority.

But they refused Sam a caseworker, explaining that there are two waiting lists. To get Sam on the short list, we would have to fire her psychiatrist and hire the one who works for the center. We declined. We like our daughter’s present psychiatrist. (This practice is illegal, but what quality of services might Sam get after Mom got the center into trouble?)

Her group home was clean, attractive, and highly structured. Sam liked it. But it turned out to be in a different mental health center catchment area, so we had to apply all over again. The new center just refused her both case management and psychotherapy. Like the first, its motto is “one-stop shopping or no services at all.”

We imagined she would live at the group home perhaps 6 months while her medications were fine-tuned (her diagnosis has recently been shifting between bipolar disorder and schizoaffective disorder), then be eased into a supervised apartment. But 3 weeks after unpacking, Sam phoned home excitedly: “I’m getting an apartment all by myself in another town in a week or two!”

I was petrified (also very angry). At Sam’s team meeting, the group home’s director was forthright: the home had 6 bedroom slots in this town and 6 apartment slots in the other. The apartment-slot worker needed more to do, and more kids were coming down the pipeline toward bedroom slots. The faster Sam could be moved out, the better off the organization would be. Jim and I protested but didn’t think to make the organization register our protests in its minutes or change her goals list before we left. Live and learn.

Sam has never held a job. She knows no one in the group home’s community, let alone the small city where her apartment is to be. She’s a “country mouse” who’s never lived on her own in her life. The director’s plan was that someone would phone Sam daily to ask if she had taken her medication (she takes five different meds a total of six times a day) and visit once a week to see if she’s OK. Sam can’t manage a medication schedule. She could get psychotic fast if she forgets her gabapentin and olanzapine.

Should I yank her out before they can put her at such risk? I’d have to start the group-home search from scratch, with no guarantee that the next one wouldn’t do the same thing. Sam can’t live at home. Having one or two family members trying to manage a loved one’s severe and chronic psychiatric illness is no easier now than it was 30 years ago. I’m gathering information to arm me for negotiations with the place where she is now.

I finagled a neuropsych eval to get an official estimate of Sam’s current capabilities. That report has been slow to arrive, so I just finagled an occupational therapy eval that will soon produce a list of specific developmental tasks she needs to master at the group home before living alone. The occupational therapist phoned us yesterday to say that Sam is capable of rote learning at best. She has almost no skill at higher-level conceptualization. She can’t anticipate cause and effect before doing something or even guess what might happen while doing it: she can only grasp the effects once they’ve occurred. She can match her actions to a sample of what she’s supposed to do, but she can’t anticipate what might happen if she did something differently.

Her memory problems make even rote learning difficult. She’s going to need to work on a daily structure (take first pills with breakfast, remember to lock up and take the key when leaving) with someone who will check on her daily and also monitor safety—Sam is in danger of leaving the stove on, for example.

It now looks like the group home will let her spend days at the home, to experience some structure and perhaps work on learning a routine, for at least a week or two before she’s in her apartment full-time. They found her a job at a fast-food restaurant, where she was quickly demoted from drive-through window to cleanup thanks to her inability to learn which menu items go together.

Jim and I have filed for guardianship and conservatorship (Sam has cofiled to support this) so we will be able to hospitalize her if she decompensates under the stress of living alone. We do understand why it’s hard for the largely untrained group home staff to grasp her deficits. On the surface, she’s fine. Our “visitor” from probate court, while supporting guardianship, described Sam as “a very intelligent young lady” four times in his report.

Sam wants to give that precollege program a second try in the summer of 1999, when she’ll be 20. I’m weighing the risks and benefits and wondering what it would be like to set up all these supports in another state. She still holds with near-delusional intensity the belief that if she can just talk to a certain boy there, her desperate love will be reciprocated (he has not responded to her calls or letters, and the head of her college program tells us that he barely remembers who she is).

Despite the effectiveness of today’s antipsychotic medications, Jim and I have gradually realized that Sam’s care remains our day-to-day responsibility—one unlikely to end while we live. Yes, there is community mental health care now, but it’s fragmented and underfunded. Professionals in one corner have no idea how to link clients to other corners, and agencies are trying so hard to keep afloat that money, not patient care, is often the prime concern.
“Close down the snake pits!” reformers shouted half a century ago. But can Sam and Jim and I trust now, any more than I could trust in 1965, that the snakes have been charmed away?

Postscript

Sam is now 21 and has been living in her apartment about 18 months, with substantial support services. She’s stable on gabapentin, buproprion, modafinil, olanzapine, and levothyroxine and doing better than we’d dared to hope. She remains desperately lonely for close peer relationships, but at last has started volunteering in her community.

We recently discovered that Sam has Velo-Cardio-Facial Syndrome (VCFS), a chromosomal deletion at 22q11.2, though she didn’t have the cleft palate or heart problems that usually prompt FISH (fluorescent in-situ hybridization) testing. This diagnosis puts a “handle” on a basketful of signs and symptoms she’s had since birth, from failure-to-thrive to thyroid failure to attention deficit hyperactivity disorder to psychosis. My first thought was, “Wow—my mother must have had VCFS!” But my husband and I both had negative FISH tests.

Sam reads complex books with comprehension, yet despite great motivation and the help of a vocational rehabilitation job coach, she has been unable to hold even a dishwashing job; she works slowly and rigidly, and can’t multitask. She lives on SSI ($500/month) and food stamps. On Jim’s birthday, she wanted to prepare his favorite meal—so there was Sam in the grocery line, buying lobster with food stamps and ignoring cutting glances from the checker and other customers. She’s an awfully sweet—and brave—kid.