

ELDER GUARDIANSHIP: LISTENING TO THEM

By [Barbara Peters Smith](#) , Herald-Tribune
/ Monday, December 8, 2014

For a 66-year-old used to being active, daily life in a Sarasota institution that caters to elders with dementia can be tedious. Linda-Kaye Bous looks forward to appointments in the hair salon, and visits from her sister-in-law. She tries to keep up with the outside world by watching TV and reading newspapers.

She is not allowed to leave the locked assisted-living center where she passes time in a 9-by-10-foot bedroom — part of a space she shares with a woman who cannot remember Bous from one day to the next. “It’s too bad, because I love her,” Bous says. “I try to take care of these people here, because I feel sorry for them.”



Linda-Kaye Bous, 66, has been living in a locked assisted-living facility since May. “This isn’t where I plan to spend the rest of my life,” she says. (Staff photo/ Barbara Peters Smith)

Since April — when she was still reeling from the death of her husband in January — Bous has been a ward of the state of Florida, with no right to make decisions for herself. A court ruling declared her to be incapacitated after a hearing in June that she did not know she could attend, held after she had already been removed from her house.

Bous insists that she does not have dementia. Her sister-in-law, Jane McElree, says she does not understand how someone as “mentally sharp” as Bous could wind up living like a virtual prisoner. “To me, it just seemed too secretive,” McElree says of the process. “This is so wrong, and it’s got to stop.”

Florida’s elder guardianship system, designed to intervene quickly for the protection of frail and vulnerable citizens, can appear opaque to anyone hoping to challenge its rationale. Once its legal wheels are in motion, trying to keep an individual from becoming a ward of the state is nearly impossible for those who lack money, access and an understanding of the rules.

Critics have a name for the efficient formula guardians often use to take over the property and lives of their wards: “Liquidate, isolate, medicate.” For Bous, the isolation is tough to endure. Her guardian, she says, has told her she cannot afford a cellphone. Attempts to reach Bous at the center often end in a hang-up, and when she places calls on the home’s shared telephone, her conversations are never private.

At night, Bous lies awake worrying about her house across town, a lifetime’s worth of possessions and the three cats she had until May. As a native of Scotland with Canadian citizenship as well, she also frets about her U.S. residency status because her husband is deceased.

So she often sleeps late in the morning, because she is weary and there is little else for her to do. On a recent afternoon a pianist entertained residents in the center’s living room, singing “New York, New York” to the clear enjoyment of the elders seated there. “It’s always the same music, over and over,” Bous said with a wry smile. “It can get a little depressing.”

A human rights issue

Bous’ situation is a far cry from the way legal experts say the adult guardianship system should work.

Florida’s statute is considered one of the best in the world, but its practical application has been criticized by advocacy groups and elder law scholars as paternalistic, ruthless and even corrupt.

This public-private system patched together to safeguard elders from fraud, neglect or abuse runs on little money — most of it coming from the wards themselves. The confidentiality of court records and lack of oversight invest two individuals with

enormous power: first, the judge who determines a person's incapacity, often without ever meeting that person; and second, the guardian who oversees every aspect of the ward's life, up until the moment of death.

The Florida Legislature may be moving toward modifications to the statute, which has been overhauled before in response to guardianship scandals in the 1980s. This year, Rep. Kathleen C. Passidomo, R-Naples, convened a group of attorneys to revisit the question of reform.

She believes it will be a matter of updating and modernizing the current legislation. She hopes to “put more teeth” in its provisions, making the state system more uniform and finding a way to scrutinize attorneys' fees.

“The statute itself is by and large a good law; there are a number of suggested changes, but it's not like we want to throw the baby out,” she says. “I guarantee you, no matter what we come up with, everybody's going to have a problem with some of it.”

Meanwhile, world and national leaders in the field are calling for far more than statutory tinkering at the state level.

They seek a paradigm shift that would make full guardianship a rare last resort, using family mediation, “person-centered” approaches and “supported decision-making” instead of an all-or-nothing court process that strips citizens of their rights and their property.

New ideas call for making it easier for wards like Bous to challenge court decisions, and giving even elders with dementia as much autonomy as possible — taking cues from the way they have spent their lives to place their unique personal wishes before their so-called best interests.

America is not alone in dealing with the challenges of longevity and dementia, and other countries have responded in novel ways. Japan has rewritten its guardianship law to honor individual rights. Germany requires judges to meet with prospective wards in person. The United Kingdom has new transparency laws that subject judges' decisions to public scrutiny.

Denzil Lush, a senior judge of the Court of Protection in Great Britain, says the change was in response to “bad press calling us a secret court.” He believes posting court rulings online has improved the process.

“You find yourself writing an opinion not only for the parties,” he says, “but for others who may be reading it.”

So far there seems to be little U.S. interest in making the adult guardianship system more transparent. But some observers believe the baby boom generation will demand more public oversight and individual rights for people who may lack capacity.

“Human rights are not something the government gives us,” says Kristin Booth Glen, an author of New York’s guardianship law and a former state judge. “They are something every one of us has because we are human.”

But skeptics point out that a patchwork system that varies from state to state, even county to county — with local interests vested in the status quo — reflects a culture with little concern about giving voice to the old and infirm.

“Sounds good, doesn’t it?” says elder law attorney A. Frank Johns, chair of the National Guardianship Association. “But from the perspective of the United States, the idea of person-centered relationships is a dream. To have this in more than 50 jurisdictions is beyond a dream.”

Ideally, in a person-centered guardianship, someone like Bous — who recites names, addresses and telephone numbers with the precision of someone half her age, and greets a reporter after a week’s absence with an exact recall of where the conversation left off — would not be confined to a locked center.

Even current Florida law calls for a “residential setting best suited for the needs of the ward,” and stipulates that the guardian “may not restrict the physical liberty of the ward more than reasonably necessary.”

But it does not require any monitoring or review of guardians’ decisions, except for audits of their spending. Once a ward’s case is closed — as Bous’ was in August — the guardian’s power is all but absolute.

If mistakes are made, they happen behind locked doors, to people whose voices are too faint for society to hear.

The lights go out

Bous’ husband of nearly 27 years — Joseph Anton Bous, a longtime coach in Sarasota schools — died at the age of 66 last January, leaving her alone in their three-bedroom

house on a quiet, leafy street in Sarasota. She was devastated for months, unable to eat properly or even pay the bills. It got so bad, finally, that her lights went out.

Someone apparently placed an anonymous call to Adult Protective Services, the state agency charged with cases of elder abuse or neglect. Bous remembers a nice man who came by and arranged to have her electricity turned back on.

Bous says when she talked with her court-appointed emergency guardian, Ellen Himes, her impression was that she was going to the facility for a few weeks' rest and recuperation.

"We were sitting out in front of my house," Bous recalls, "and she said, 'There's a place I know of and they have a room that's open and maybe you should go there just for a little while. It will help you feel better. Take a few clothes.'"

Himes said she could not discuss Bous' case specifically, "due to privacy issues of HIPAA" — the Health Insurance Accountability and Portability Act — "and other confidentiality issues surrounding the ward." But she said helping a ward make the transition from an unsafe environment often requires tact.

"I never tell them that they'll never go back to their homes," she says. "I try to guide them around it in a better way, like, 'You're going to go live in a resort now,' as opposed to, 'You're not going back to your house because it's too big and you can't handle it anymore.'"

Himes says she has 15 wards, but only four that she is paid to oversee, because the rest have no money. When she agrees to take a case, she says, she has no idea of the person's financial or health situations. She sometimes has to scramble to find a facility that will accept her ward with no guarantee of payment.

"I always try to give them a better option than where they are now, because they know in their head — even if they have dementia — that it's not working," she says. "I never lie; I say, 'This is the place we have for right now.'"

"I have four of them who think they're living in a resort," she adds. "It doesn't matter, because they're happy." Usually, Himes says, when she goes through wards' mail, she finds that they are "deeply in debt."

Bous maintains that she has asked Himes to bring her correspondence to the facility.

“I haven’t received any of my mail for six months now,” she said in October. “I keep saying I know there is mail I should be seeing. She says it’s mostly all junk mail. Do they think I’m stupid?” But Himes says her wards’ mail consists mostly of bills.

“I have gotten only one personal letter in my entire time as a guardian,” says Himes, who received her license in 2009. “These people that I have, they have nobody or they are estranged from their children.”

Sometimes, she adds, the guardianship process can cause a family to reconcile.

“I’m the guardian, so I’m the bad guy,” she said, “and the children are back in good graces and they can love each other again. I love it when that happens.”

Himes says that only two of her wards have been pleased at first to have a guardian.

“Everybody doesn’t want it because they know that’s the end of the road,” she says, and her job is to tell them, “You’re not going to die; you’re going to have a good life; we’re going to do fun things with you.” One ward, Himes recalls, simply didn’t like her face.

“This lady hated me for the first month,” she says. “I kept on, kept on. On her deathbed, I was the one she asked for.” 'He was difficult'

Bous has a gentle, friendly manner but a steely will — perhaps forged in her lifelong struggle with polio, contracted when she was 5 months old in Scotland. Her family moved to Canada, where the Rotary Club paid for her medical care.

“I’ve had operations all my life, every year all through school,” she says. “It’s made me tough.” Bous walks with a slight limp, and says she needs surgery again. “On one of my feet, the toes have moved to the side,” she says. “I had a good doctor; he was going to straighten them out. But I haven’t been able to do it because this has set me back.”

Aside from her Canadian relatives — with whom she has lost contact since becoming a ward — Bous has only her sister-in-law, who recently retired to Sarasota after a teaching career in Fort Myers. Both Bous and McElree say the last few years of Joseph Bous’ life, as his health was failing, were traumatic.

His angry outbursts brought visits from sheriff’s deputies, they say, and after he had an altercation with the mail carrier, the Post Office refused to deliver to their house. When he wrecked their car, Bous says, he demanded that she get behind the wheel; as a result her driver’s license was suspended.

“The diabetes took his personality and everything from him,” McElree says about her only brother. “He became someone you wouldn’t recognize. The strokes were taking over, and he was difficult.”

Such decline and turmoil, followed by a death, can bring on an extreme form of grief that looks like post-traumatic stress disorder, says Jim Monahan, the executive vice president of community engagement for Tidewell Hospice, and a specialist in bereavement.

“It sounds like she went into a severe state of depression — which wouldn’t be considered the normal grief reaction, but it certainly can happen,” Monahan says, on hearing about Bous not paying her bills. “She was probably looking after him all the time, and putting her needs second.”

McElree says she tried to help out, making funeral arrangements for her brother and picking up the Bouses’ mail. The guardianship process, she maintains, happened so swiftly that it caught everyone by surprise.

“She was not capable at the time,” McElree says of her sister-in-law. “She was a grieving widow who never got a chance to mourn properly. Obviously, in her situation she needed some attention — but not this.”

'Caught in the flow'

Because the U.S. guardianship structure is so underfunded and fragmented, advocates say, no reliable data exist to make a pressing case for reform. Nor is there an adequate system of oversight in most of the 54 or 55 separate systems in the country.

“Monitoring is the hottest issue the courts face,” says Brenda K. Uekert, principal research consultant for the National Center for State Courts. “Nationally, if I had to grade it, I would give the courts an ‘F.’ Most courts do not have investigators, court visitors or even volunteer monitors.”

In Florida — with its concentration of elders living far from their hometowns, who routinely fall prey to scam artists and profiteers — the need for scrutiny is even more pronounced.

Sarasota County Clerk of Court Karen Rushing says hers is one of the few among 67 Florida systems that has a strong guardianship auditing process in place. Adding regulations could be costly, she points out, and a further drain on wards’ assets.

Still, she acknowledges that the status quo can be bewildering for wards and their families.

“I think the war stories that exist are very compelling,” Rushing says. “You can just get caught in the flow, and you can’t get out of it. You feel like there’s no one you can really talk to, because everybody’s singing from the same hymnbook, and they’re not coming off that page no matter what you say.”

To navigate the system, prospective wards should have a stronger legal advocate — just as someone accused of a crime is entitled to a defense, says Diane Menio, executive director of the Center for Advocacy for the Rights and Interests of the Elderly in Philadelphia.

“When we talk to wards’ attorneys, they see their role as protecting that person,” Menio says. “I think that’s the role of the petitioner, or the judge — not the ward’s attorney. We don’t have attorneys in court speaking on behalf of that person.”

Wards and their families are often denied a fair hearing because judges are too quick to see the potential for neglect and abuse, contends Catherine Anne Seal, a Colorado elder law attorney who is active in national guardianship issues.

“Families do things under a family system, solving a problem the best way they know, and don’t understand what the legal rules are,” Seal says. “I’ve learned to be more forgiving of a family system and believing in their motivations. Not every case needs litigating.”

Linda Fieldstone, family court supervisor for the 11th Judicial Circuit in Miami, believes the key to involving wards and families in decisions lies in intervention before the guardianship process kicks in. She has spent the past few years building massive task forces to study “eldercaring coordination” on the state and national levels, involving 41 organizations.

“I think it was pretty miraculous; we all saw the same need — the idea that a one-size-fits-all system for everybody is just not appropriate,” she says. “I found that when I started talking to people about the flaws in adult guardianship, we were finishing each others’ sentences.”

Conflict resolution, Fieldstone says, should happen before any judicial process. Many guardianship judges already send complex cases to mediators, she adds, but this has limited success for families with a lot of dysfunction. “They aren’t going to do well in mediation,” she says, “because it’s just another opportunity to vent. Those are the ones who need the hand-holding.”

Fieldstone envisions the same kind of coordination services for elders that now exist for high-conflict divorces that affect children. Addressing their issues upfront, she argues, could avoid the adversarial nature of a guardianship proceeding.

“We found that with parenting coordination, gradually circuits opened up to the idea,” she says. “So there’s precedence for this in Florida.” Still, Fieldstone agrees with Passidomo, the legislator, that statewide reform will be incremental. “It has to trickle down,” she admits. “Some circuits will be very receptive, and others don’t want anything that’s going to disturb the equilibrium of whatever that circuit does.”

One question is whether change will happen soon enough for people like Linda Bous, who must now depend on a relative stranger to shop for her toiletries and sort through her belongings. “No matter how well-intentioned a guardian is, it’s the guardian who makes the decision,” says Kristin Glen, the former New York judge. “At the end of the day, that is a huge deprivation of human dignity.”

'A lot of living'

One Saturday in October, desperate for help, Bous called the Herald-Tribune newsroom.

A reporter visited her at the center, and then spoke to Marc Soss, the attorney originally assigned to represent her. Soss said he could not discuss her case in public. But, in a rare move for a court-appointed ward’s attorney, he agreed to talk to Bous and consider re-opening the case.

Last week he filed a “Suggestion of Capacity” on her behalf — the first legal step in getting her rights restored.

Throughout her ordeal, Bous has been fortunate in one regard. Her house and possessions have not yet been sold — because Himes, her guardian, has not completed the inventory of assets needed to close her late husband’s estate. The latest deadline extension, according to court records, gives Himes until Wednesday to complete this paperwork.

Himes says the fact that Bous will get a hearing in court is “evidence that the system works.” If Bous succeeds soon in becoming one of the few wards able to convince a judge to let her manage her affairs, she could possibly have her own home still available to welcome her. She can’t wait. “Before I came in here, I was looking for a laptop; I’m lost without a computer,” Bous says. “My relatives and my girlfriends will all be wondering what’s wrong with me. “This isn’t where I plan to spend the rest of my life,” she adds. “I’ve got a lot of living to do.”