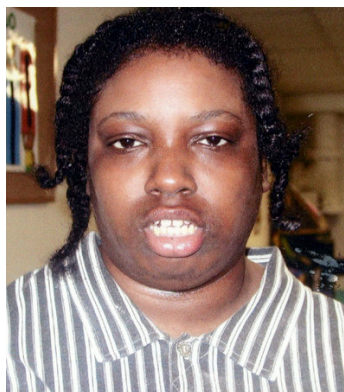


They must care for the disabled. But who cares for them?



By [Ronnie Polaneczky](#), Daily News Columnist

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FOR TOO LONG I have listened, aghast, to stories shared by Dee Coccia.

She's co-executive director of Vision For Equality, a nonprofit that advocates on behalf of intellectually disabled folks and their families.

If you don't know anyone who has an intellectual disability, your eyes probably just glazed over and you're now turning the page in search of a more exciting read.

But if you do know someone with an intellectual disability, Cocchia's stories will be horrifying and, perhaps, familiar.

Here's one of them.

"We're trying to help a mother whose older autistic son had suddenly become hard to handle - he was acting out and becoming violent," says Coccia, 75. (Her own daughter, 50, is intellectually disabled and lives with Coccia and her husband, 77, who are their daughter's primary caregivers.)

"He needed crisis intervention, and then he needed to be committed to a group home for constant care. But no group home would take him. So instead, he's in a regular hospital, heavily sedated. He's been there for two months. At this point, his care has cost the state tens of thousands of dollars. The hospital won't let the mother see him, because when she visits, he gets upset. Well, no wonder: He's in a hospital, where he shouldn't be."

Then there's the story of the 80-year-old mother who was caring alone for her intellectually disabled son, who was in his 50s. The son was helping his frail mom climb the stairs when she fell and died. He sat with her for five days, until it occurred to him to ask a neighbor for help.

"If he'd had a caseworker, someone would have checked in on him and he and his mother would've gotten help sooner," says Coccia.

But the son, and thousands more Pennsylvania citizens with intellectual disabilities, was on a waiting list for state aid that would pay for such help. The list is currently about 14,000 people long.

Even when families finally receive the assistance they need, there's no guarantee it will be competent.

Patricia Sankey had state-paid help for her severely disabled daughter Christina, 37, who had the intellectual capacity of a toddler.

In March 2014, the caregiver, Ayesha Wulu, took Christina shopping at Macy's in Center City, where she lost track of Christina and waited an hour to tell police. Christina was found dead the next morning in West Philly. Frozen to death.

After I wrote about Christina's death - which no one but her aging mother appeared to take seriously - a grand jury was convened to investigate. As a result, the caregiver has been charged with reckless endangerment and felony neglect.

I was glad Christina's death finally got the scrutiny it deserved. But I didn't know where to start with the scads of stories it generated from other families with intellectually disabled loved ones.

They contacted me to talk about caregiver abuse and agency incompetence. About political and public indifference to the needs of intellectually disabled adults. About the lack of compassion and resources for elderly parents who have become too old and frail to care for their aging, impaired children.

Their stories barely scratched the surface of an issue that is rolling toward us like a tsunami: Experts say we will soon have more intellectually and mentally impaired adults living in this country than at any time in our history.

Advances in medical care have allowed children born with Down syndrome, for example, to live twice as long as they did just 20 years ago. And the explosion in the number of children with autism - one in 68 kids are now diagnosed - means we'll soon have a vast population of adults in need of services like those Christina's family had hoped would keep her safe.

How in the world could I begin to address all of this in a column?

Until now, I couldn't. I didn't have the resources to give the issue the attention it requires.

But this week, I was awarded the 2015 Pulliam Editorial Fellowship, whose \$75,000 stipend will help me tear into this issue over the next 18 months. I'll learn what works and what doesn't in the treatment and care of intellectual disabilities. Find out how public dollars are being spent. See which agencies are doing excellent work and which ought to be shut down. Identify the heroes and villains in a field that has both.

And then I will tell the stories in this column. Which is where you, awesome readers, come in.

If you are caring for a loved one with an intellectual disability, please email me at polaner@phillynews.com and tell me how you're faring. Tell me your wish list for your family member and for yourself. Tell me what it is like to be the person responsible for the well-being of a forever-vulnerable loved one.

And then let me use this column to amplify your voice. Because not enough people with the power to help have been listening to your cries of desperation.

Perhaps they're hard of hearing. So let's make a ruckus. Your loved one deserves it.

And so do you.