

Looking for a place for Mickey

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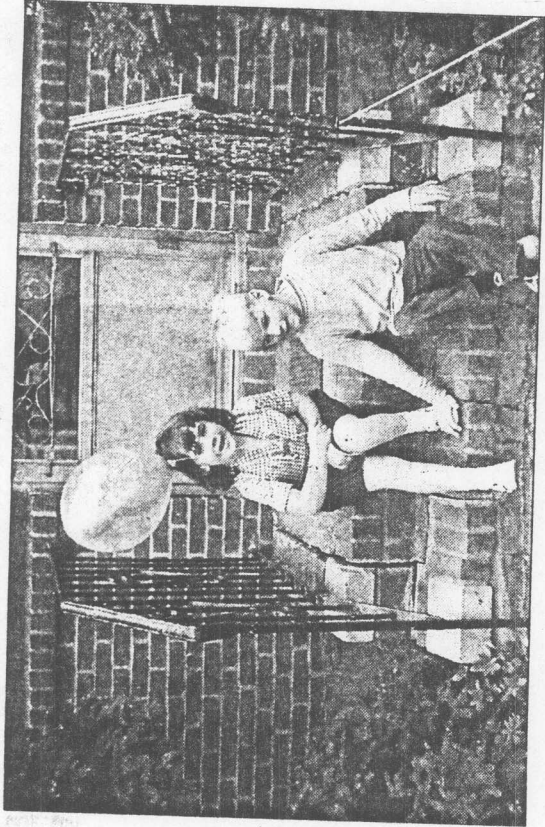


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Business writer A.J. Connelly with her brother, Mickey, on Memorial Day, 1970.

Personal reflections on my mentally retarded brother moving from Mom and Dad's

BY EILEEN A.J. CONNELLY
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If the state really is committed to getting rid of the lists of developmentally disabled awaiting community residences, it means Michael will finally be moving out soon.

My brother, who will turn an unbelievable 35 years old in a few weeks, still lives with my parents, both of whom will hit 65 this summer.

Although his developmental abilities place Mickey, as we usually call him, somewhere between 2 and 8 years old, depending on which skill you're examining, he is physically 35. He's a big guy, a handful to handle. And as my parents age, I can see the strain it places on them to care for him: Bathing, dressing, even just trying to convince His Stubbornness that he has to get up out of bed some days.

In many ways, they've been caring for an infant all these years.

Had my folks listened to the advice of the experts back in the late 1960s, when the diagnosis of severe-profound brain damage was finally determined, Mickey would have been moved to a community residence years ago, that is, assuming he lived through the first level of horror that the state offered.

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"Put him away," they said. "You have other children. Forget you had him."

Although my parents had four other children — including me, born just 15 months after Mickey and well on the way into this world before it was known there was anything "wrong" with my brother — they took one look at Long Island's old Suffolk State School, not far from our home, and decided they'd rather take on the unknown than condemn him to hell.

Staten Island's Willowbrook became the catchword for the state institutions where people like my brother were warehoused, neglected and abused, but rest assured, that sort of place didn't vary much from county to county or state to state.

It's easy to assume that Michael would have died from one of his nighttime coughing fits — we both have respiratory problems, although these days mine are worse than his — if he'd become a ward of the state 30-odd years ago. But he had made it through that sys-

tem — against the odds — he would have moved to a community residence when the institutions finally closed in the early 1980s.

Instead, Mickey lives in the same place he always has.

Through luck and God's grace, my parents found a wonderful day program where he's been thriving for more than 25 years — the Association for the Help of Retarded Children in Brookville, L.I., a parent-driven organization that has created programs and pioneered education methods.

Mickey started going to their camp at Hunter Mountain a few summers ago and, since my grandparents became too old to help out when my parents need a break, he stays at a respite house for the occasional weekend and vacation.

For years my parents have resisted the idea of Mickey moving to a community residence before their deaths, but the increasing age of my grandparents need, recent bouts with their own illnesses and the simple process of aging have nudged them closer to accepting that it might soon be time. They put his name on the waiting list a few years ago, figuring when his name came up they'd be ready.

Being a sibling, rather than parent, it's easier for me to say "it's time." Although I've always had a role in caring for Mickey, and would be willing to take him into my own home if the old state institutions were the only choice, it's also easier for me to see that he'd be better off on his own.

I'll never forget a discussion eight years ago with a woman whose son lived in a community residence.

That mother said she knew her then-18-year-old wasn't getting the same care he would have at

home, but asked me what kind of care he would be giving himself if he were "normal" and away at college? Certainly, she said, not the care he would have gotten from his mother.

Nor do I treat myself the way my parents would if I lived with them. They'd make sure I'd get more sleep and eat better and so on. But as an adult, I've made my own life, for better or worse, and Michael deserves the same opportunity. He'll need more help than I do, of course, but most importantly, he'll need a place to live: A roof over his head, a bed to lie down on, a place to plug in his VCR and store his ever-growing collection of videos.

As a homeowner, I understand the concern people have when they fear something "bad" coming to their neighborhood. As a sister, I'm angered to tears when I hear misinformed people screaming ridiculous accusations about retarded people coming to rape and pillage. If that's ever happened,

I've never heard about it. The worst thing my brother ever did was walk down the street pushing a neighbor's lawnmower because he's fascinated by the noise they make.

Community residences are homes. They're where people like my brother live. They come home from their daytime activities — school or work, depending on their abilities — and together they prepare and eat dinner. They watch TV or play a game. They may go out to see a movie or bowl or play some other sport in the evening, then come home and go to bed.

Sounds pretty much like what goes on in every other house on the block, doesn't it? The main difference is, these "families" need a little help from a few heroic people who are willing to work with them.

Since I was a child, I've attended more community meetings about the placement of community residences than I want to count. The screaming and yelling, the fear and ignorance are always the same. The arguments against opening range from the outright insulting to the seemingly reasonable.

Some of the "antis" seem to think the agencies picking locations don't consider whether the local bus service will be adequate or there's a grocery store close enough. They voice "concern" that the agency made a mistake and the location is somehow "inappropriate." I've yet to run across an agency that sought to make this difficult work harder than it is by picking bad locations.

Those who raise the specter of increased traffic in quiet neighborhoods will never admit they have no control over how many cars any other family down the block might have. Issues like noise also are uncontrollable when a home is purchased by random individuals. In fact, when an agency opens a home in a neighborhood, it has every reason to be as communicative with its new neighbors as possible, since the support of those surrounding makes life easier.

Who can say such a thing about the boor down the street who mows his lawn at 6 a.m. on a Saturday or allows his teen-agers to run wild and terrorize the neighbors? What about the jerk who lets his trash pile up in his driveway for weeks on end, or the slob who hasn't painted the house in decades? Which hurts the "quality of life" or "property values" more?

Thankfully, state law makes it pretty difficult for neighborhoods to keep community residences from opening. And a few months or years after they open, the houses rarely are a problem. Ask some people who live near them on Staten Island. Many probably don't even know their neighborhood hosts a community residence.

From the editor

The only thing I can say to people who don't want "those people" in their neighborhoods is, "look around." They're already there.

The expression we often use in my family is, "everybody has somebody," meaning almost all families have some form of disability somewhere in the family tree. Amazingly, many of those screaming "not in my neighborhood" have close relatives who need the same kind of care.

What do they think will happen to them?

Sunday's headline kicking off the Advance's four-part series on the mentally retarded and other developmentally disabled adults was troublesome for some.

We received a number of telephone calls from Staten Islanders upset over our use of the word "retarded" to describe the people who live in the community residences that have become a flash point in some communities.

Since Willowbrook, "we have worked 25 years to change all that," said one caller who works with the developmentally disabled. "We tell them they are special, not retarded," she said.

The decision to use "retarded" in the headline was not made glibly and the intent, certainly, was not to insult either the residents, their parents, or the staffs.

Rather, it was an attempt to clear confusion over exactly who will be living in the 40 community residences that local human services providers estimate the borough needs to comply with a new state law.

We intentionally avoided vague terms like "disabled" or "special" so readers would know up front exactly who we are talking about — the mentally retarded — because many are under the erroneous impression these residences will house the mentally ill or recovering drug addicts or troubled teens.

Even though "retarded" has taken on a derogatory connotation through misuse, it is still a valid diagnosis that many in the human services and medical fields continue to employ.