

COMMUNITY INCLUSION ??????

The following e-mail was sent to our mailing list group of parents of special needs children.

Hi to all who have posted eloquently and in a heartfelt way on this important topic. You have all expressed the problems that can be spawned by the notion of “inclusion” in the educational and public school setting. The post I am about to write describes a problem with the idea of inclusion that extends beyond the problems of our APD children. So it’s off-topic. But I am writing it to show how it affects the world of adult special needs kids –who have aging parents that they will outlive some day.

Let’s look for a minute at the word “inclusion.” It sounds like a nice, cozy word to describe the way we, as a society, would like to treat those with special needs. It sounds like the way you would like your special needs family member to be treated – because the opposite of “inclusion” would be “exclusion” – right? So it’s automatically accepted as the way to go, particularly by those who have no first-hand knowledge of the special needs. “Inclusion” can be a dangerous word.

My family has been trying to gain support for a residential community for adults with special needs. What we envision is a place where these adults can live and work while they are cared for and sheltered so that their most basic health and safety needs are met. We envision a place where the jobs that these adults have contribute in a meaningful way to the well-being of the whole community. We want to have a place where my brother can take a walk safely, without fear that he’ll get lost or hit by a car. If his best contribution to the group is being a superb organizer of kitchen utensils and a first rate dishwasher-unloader, we would like him to feel proud of that and know that he belongs.

Our vision is that people from outside the community would take part, and that residents of the community would have opportunities to participate in outside work opportunities if they are able. This is not an “institution” or a place with unbreachable walls.

The problem is that in our state, the word “inclusion” means that adults with special needs are forced to live in isolated settings like group homes, where there is little or no contact with neighbors. The residents are merely shuttled back and forth to their workshop settings where they do piecework like stuffing envelopes. This is under the guise that the residents are “out in the community” and thus “included.” My brother once got a paycheck from a workshop like this for, believe it or not, 13 cents. Less than the stamp it was mailed with!

Inclusion in our state precludes the development of community based residential settings. For the more seriously handicapped, like my brother, there are no choices – he simply can’t be left on his own to sink or swim, to risk getting lost on a bus if he can’t ask for or understand directions.

In our state, again the dangerous word “inclusion” conjures up ugly images of the alternatives – people automatically think of horrible institutions such as the 70’s-era Willowbrook.

My 35-year-old brother has Down's Syndrome and autism, and can't express his own needs to others beyond simple phrases. He can't answer an abstract question, doesn't know his address, can't write other than his own name, can't read.

We still hope to get the project off the ground. But zealous "community inclusion" believers would like to put up obstacles at every turn.