

The “Right” to Live Where You Want ... HUH?

#Aut2know – Opinion – Dan Torisky

The following commentary applies to children and adult-age individuals on the autism spectrum who do not possess the mental capacity to make informed decisions regarding their short and long-term welfare, and hence must rely on their caring parents or guardians to make these decisions for them:

Let me share my personal example: So, perhaps my 58-year-old son with autism wanted to be able to choose where, how and with whom he would live. Giving him his choice, many years ago, would have meant him living with his parents and his siblings, with all of us accommodating his screaming, tantrums, obstreperous behaviors, habits and mannerisms, both here in our house and neighborhood and in public places, giving him what he wants when he wants it, regardless of the inconvenience and annoyance to others.

Instead, we chose that he would live for a time where he got the residential care and treatment, the intensive behavior-shaping and the habilitative training he needed in order to eliminate or reduce his disabling characteristics to the point where he – like his non-autistic brother and sisters – could enter our community on the community’s terms -- to the fullest extent possible. It worked out: he lives in a supervised group home, has a job. He visits, we visit, share holidays, trips. No family is closer.

Yet, the illogical notion currently persists as gospel from other advocacy groups that those with special needs have the “right” to choose how and where they want to live and with whom, and it somehow is the responsibility of society to make it so, regardless of their capacity to make informed decision or without consideration of their highly specialized needs. No child, gifted or special needs or anywhere in between, has this “right”, or the “right” to be given, this choice – or ever has had this “right” in civilized society. It is a pre-requisite to have judgmental competence and possession of self-sustaining ability, both of which are acquired over time and development of the skills to enable survival and the overcoming of the challenges of genuine community living.

Another example pertains to the “least restrictive environment” (LRE). LRE to the fullest possible extent certainly is possible, but given the cost in money and human suffering this possibility is impossible. The words “possible” and “appropriate” are not interchangeable, let alone synonymous. Realistically, however, “appropriate” is always possible. If the mandate were to read “fullest extent” appropriate, it would indeed be possible. But when “possible” is defined as full accommodation at the expense of hardship to others, and/or denying or hampering others, the opportunity of others to learn, strive, earn and grow, “possible” becomes unjustifiable.

The social engineers never quit. Not only do we have “possible” being defined as “appropriate”, and “want” being translated as both a “need” and as a “right”. Now, just as absurd, we have “segregation” being defined as “discrimination”, hence giving rise to the CMS Home-and Community-Based- Services (HCBS), “Final Rule”.

This Federal bureaucratic diktat defines the accommodation of special care and treatment needs of a person in a necessarily congregate setting as “segregation” and “discrimination”, with all the negative connotations these words have to imply. Nevertheless, these unelected policy makers are decreeing that the non-special needs population have the obligation to give special needs people what they want, whether possible, appropriate, justifiable, or not.

The basic right of any individual to communicate his or her wishes for care or treatment must be viewed in the context of the capacity that person has to make such decisions.