

Whose Choice is It and Where is the Diversity?

The following letter was sent as a comment on VOR's "When Equitable Does Not Mean Equal: Respecting Diversity and Choice" (October 2013, *EP* magazine)

Dear Sirs:

It is very interesting when an organization that does not believe in choice, diversity and equality uses those words to describe their principles. Their very name, the Voices of the Retarded, denotes antiquated language that does not reflect respect for people with developmental and intellectual disabilities.

The only choice the VOR is referring to is the choice to live in an institution. And, according to the Merriam-Webster Dictionary, diversity means "the quality or state of having many forms, types, ideas, etc." and equality means "the quality or state of being equal: the quality or state of having the same rights, social status, etc." The concepts of diversity and equality could not be further removed from the reality of institutional life for people with developmental disabilities.

In a recent article, the VOR played hard and loose with the intent of the Olmstead Decision and the DD Act. If read in their entirety it is obvious that both the Decision and the Act support, condone and even insist on community living for all people with developmental disabilities. If the reader wishes to use both documents as a cook book and take little pieces from here and there to support their point of view, it is easily done, as it can be done with most documents. However, this methodology does not take away from the fact that the authors of the Olmstead Decision and DD Act believe that all people with developmental disabilities belong in local communities, not hidden away from society in institutions.

Furthermore, it is not 'misguided ideology' to believe people should live free from segregation. In fact, it is a basic human right, and our cultural heritage, to live our lives as free from isolation and restraints as is humanly possible. Just because someone is born, or acquires, a disability, that does not change the rules. Everyone must live alongside everyone else in a regular neighborhood, enjoying their community to their fullest extent. This is what is called diversity.

As a parent of a young lady with developmental disabilities I can honestly say that my 'choice' is not always her 'choice.' There have been many times in her life that I have held her back because I was concerned for her safety or welfare. I thought I was doing what was best for her, when in fact she wanted to stretch her wings and fly a little. But in letting go I was allowing her to experience things that had not been open to her while I was trying to protect her. Of course I made sure she was safe to the fullest extent possible. But I had to let go, as I did for my children without disabilities.

The membership of the VOR is not people with developmental disabilities, it is usually family members. When they write and talk about choice they are talking about their choice. That is, the family member's choice. I am not doubting that they feel they are making the right choices for their family member, and the other members of their families, but surely they cannot believe that being isolated in an institution is more satisfying or enriching than being part of a community.

Many times throughout my 40+ years working with people with significant disabilities I have been astonished by the understanding people have about their circumstances. I am constantly reminded of Bonnie, who I met early in my career in a nursing home in Texas. She was very involved physically and medically and was considered by the staff who cared for her to be nonverbal and lacking in interaction with her environment. During one holiday season she very distinctly whispered to me that she wanted to go home, she spoke to me. I have never again underestimated the wants and needs of people with even the most significant disabilities. Often we have to watch closely for clues as to their wishes, but if we take the time to do this we may be surprised to learn what it is they seek from their lives.

There are formal research studies and anecdotal reports that show that people with developmental disabilities thrive in the community. For sure, there are a few people who do not do well in community settings, for one reason or another. In fact, I would suggest it is because the home in the community was not a good fit. This happens to all of us from time to time. Even people with significant intellectual, behavioral and physical disabilities can, and do, thrive in appropriate integrated settings.

Living a life free from isolation from the general population is not ideology, it is a basic human right. Instead of fighting what is right, the VOR should concentrate their efforts on ensuring that the community is ready to offer the people they care about the fullest life possible. Indeed, life is not all about 'safety,' it is about the quality of life too. And, quality of life means happiness, satisfaction, interaction with others, having a sense of belonging, etc. We need to work hard to make sure this is the experience of all people, even those with the most significant physical, medical and behavioral challenges.

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Dear Mr. Valenzano and Mr. Rader,

Thank you for welcoming a response from Dr. Alison Lozano, the Executive Director of the New Jersey Council on Developmental Disabilities, to VOR's "When Equitable Does Not Mean Equal: Respecting Diversity and Choice" (October 2013), and allowing my reply. On behalf of VOR, I am grateful for this opportunity.

I wear many hats.

I am a VOR Board Member and also a member of the New Jersey DD Council. More important than these titles, however, are my roles as dad and uncle.

My son, Danny, has severe autism. At age 18, he still lives with me and his mother, but will require community-based services in the future.

My nephew, Benny, has Fragile X syndrome. He also lives with his father, but is involved in vocational and recreation programs and will someday need community-based residential supports.

My niece, Heather, has a profound, regressive form of autism, meaning her disability is more pronounced with each passing year. She calls Hunterdon Developmental Center home, in every sense of the word. She has a job she loves, has good friends, and receives the exceptional care and support she needs to survive. She's hardly "isolated" or "segregated," as Dr. Lozano claims. Her quality of life and care is typical of New Jersey Developmental Center residents. It's simply a myth borne in past, corrected history that these individuals are somehow shut away from society.

Dr. Lozano's reply to VOR's article begins with a claim that VOR does not believe in choice, diversity or equality. She points to a name – not VOR's name – as justification for her claim. VOR has never been called "Voices of the Retarded," and several years ago we changed our name to VOR from "Voice of the Retarded." Just as the Association for Retarded Citizens (now called The Arc) did, VOR opted to move away from "anti-quoted language that does not reflect respect for people with developmental and intellectual disabilities." On this point, Dr. Lozano and I agree.

I strongly disagree, however, with Dr. Lozano's characterization of VOR as supporting only institutional ("developmental center") care. I would not support VOR if that were the case. As noted, I have two family members who will someday want and need community-based supports, just as Heather requires more specialized care for her survival.

And, that is exactly the point: People with disabilities do not have the same needs or wants. As clearly stated in our article:

"Equitable – providing individualized care and employment options – does not mean equal [the same]. People with disabilities have vastly different needs, requiring vastly different supports across the continuum."

As a New Jersey DD Council member, my views with regard to the provision of services based on individual need and choice are well known. I have openly challenged the Council's public relations and legislative advocacy campaign in support of the State's decision to close developmental centers. As a publicly-funded entity, I believe strongly that the Council should not "take sides" in support of some individual care decisions, but not others. By vast majority, the individuals being served in developmental centers have profound intellectual disabilities. They have the cognitive abilities of infants and young children. They require the help of their families to make care decisions, just as young children do. I don't agree that it is the Council's place to question caring families who, by vast majority, are supportive of the care received in our developmental centers.

Dr. Lozano also suggests that VOR has misrepresented federal law, yet nowhere in the ADA, in the Supreme Court's Olmstead decision, or in the Developmental Disabilities Act is there a mandate to close all "institutions." These laws encourage community integration where possible, but leave the final decision to individuals and their families. The Supreme Court in Olmstead goes further, requiring individual choice and emphasizing that "nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."

VOR's support for an array of service options, from own home, family home, community-based supports and facility-based options, based on individual choice and need, sounds a whole lot more like choice than Dr. Lozano's position that "everyone must live alongside everyone else in a regular neighborhood, enjoying their community to their fullest extent."

Living in "regular neighborhoods" is a nice image, but what's "regular?" Some of us live in homes in the suburbs or in the hearts of cities; others live in condominiums, apartment complexes or college dormitories; and others choose to live in retirement or gated communities. Like all of us, people with intellectual and developmental disabilities will choose and need different living arrangements. They should not be relegated to someone else's notion of what is "regular."

My own family represents the continuum of need and I'm grateful for real choice.

Thank you again for this opportunity.

Respectfully,
Geoff Dubrowsky
Dad to Danny
Uncle to Benny and Heather
VOR Officer and Board Member
New Jersey Council on Developmental
Disabilities, Member

