

WHEN EQUITABLE DOES NOT MEAN EQUAL:

# RESPECTING DIVERSITY & CHOICE

VOR presents its

*Key Principles in Support of Ensuring the Rights and Opportunities for All People with Disabilities.*

The organization calls on the broader community of advocates to support and promote these principles.

The world of disability advocacy boasts its own language, for better or worse. In some instances for the better, hurtful labels to describe a type of disability have been replaced by words that do not yet have a pejorative connotation.

In other cases, however, terms of common usage, such as “choice,” “inclusion,” “integration” and “community,” have been incorrectly redefined to mean only certain choices or certain places according to the user’s ideology. In these instances, some individuals with disabilities have suffered due to a lack of individualized care in favor of ideology.

Consider the situation facing residents of Apache ASL Trails, an apartment complex serving seniors with hearing impairments. “ASL” is in reference to American Sign Language and Apache ASL Trails boasts architectural features designed to meet the unique needs of its residents, such as flash-

ing lights instead of doorbell or phone sounds, and wiring in common areas that pipe announcements directly to residents’ hearing aids. Beyond architectural conveniences, the complex features a sense of community among similarly-disabled residents who are able to communicate and socialize.

If this scenario involved college students or non-disabled seniors, there would be no argument from advocates or the federal government about the community and cost efficiencies fostered when similarly-situated individuals live together.

Yet, the U.S. Department of Housing and Urban Development (HUD) has filed a discrimination complaint against the developers of Apache ASL Trails, the construction of which was supported in part by federal funds. HUD alleged that the com-

plex is engaging in housing discrimination because most residents are hearing impaired and thus are not “integrated” enough with the general population.

According to representatives for Apache ASL Trails, “HUD did not interview one single deaf tenant at Apache [or] consult with any experts from the deaf community.” In other words, HUD found discrimination on behalf of a group of citizens who, quite to the contrary, are happy and “not lonely anymore.” HUD incorrectly cites *Olmstead*, a landmark Supreme Court decision, to justify its findings, yet *Olmstead* actually embraces individual choice.

Regrettably, this is not an isolated example of a misguided ideology empowered by a misinterpretation of *Olmstead*. Rather than support “inclusion” and “integration,” these actions imposing limitations that can



lead to isolation and, at times, risk.

Compare the experiences of Brian and Mark. Brian, who is intellectually disabled, experiences dangerous behaviors. When living with his family, he injured every family member and they replaced hundreds of windows. Brian has been expelled from four community homes in two states and now lives comfortably and safely in a Medicaid-funded facility for people with I/DD.

Mark, who has multiple disabilities, wanders out of his home, has little sense of danger, and is prone to outbursts. To keep Mark safe, his mother keeps very loud alarms around her home to alert her and others if he wanders from the home. "If Mark goes out of the door, then we and God and everyone else can hear it because it is so loud," she said. "But it is exhausting. It is intensely stressful and it's very exhausting."

According to current federal policy (embraced by the U.S. Department of Justice, Centers for

Medicare and Medicaid Services, HUD, and the National Council on Disability), Brian is safe, but considered isolated and segregated because he lives on a campus setting with more than three other individuals with disabilities. Mark is isolated and in a potentially unsafe situation, but considered integrated because he lives with his family in the "community." Underpinning this policy is, again, a misinterpretation of *Olmstead*.

## EMPLOYMENT INCLUSION

Advocacy and policies around the employment rights of individuals have marched down a similar path.

Competitive employment – adults with disabilities having the right to work full time and receive at least minimum wage in regular workplaces – is the ideal for many individuals with disabilities, but not all. Some individuals with more serious disabilities require reduced hours, more training, and additional assistance. For these

individuals, sheltered and supported employment options allow for a meaningful and productive day that may otherwise be out of reach.

Recognizing the need for a continuum of employment options, the New Jersey Legislature recently voted to save its sheltered employment for its citizens with disabilities:

"Supporters contend that even the work and the paychecks are just part of a larger program that also focuses on helping individuals reach goals, including increasing attention span, motor and interpersonal skills, and socialization. Many said a competitive workplace, even with support, was not a realistic goal, noting that those who can move into those workplaces do so." (*Burlington County Times*, July 29, 2013)

In other states, disabled employees who count on sheltered employment options may not be so lucky. Like other areas of disability advocacy, "choice" and "inclusion" have come to mean only competitive employment. Federal funding cuts and advocacy are pushing states to drop their sheltered employment options to provide disabled individuals the "right" to receive competitive employment. However, this could well be an empty "right." Even in robust economic times, unemployment rates for individuals with disabilities remain very high. Historically, employers have not had the time or funds to train, supervise and support someone with a disability. Sheltered employment offers alternatives for disabled workers, but if such options are discontinued, the few jobs for people with more profound disabilities will disappear along with their sense of self and accomplishment.

"For those who are not capable of working in community settings but are still capable of work, and want to work, and enjoy the company of their colleagues and the staff at a sheltered workshop, this can be a meaningful alternative – and one vastly superior to spending their days in less productive (or nonproductive) activities at their residences." (Testimony of Linda Blumkin, VOR member, before a New York Office for Persons with Developmental Disabilities Town Hall Meeting, September 13, 2013).

Full inclusion / competitive employment advocates claim to be protecting rights, yet they may actually be limiting rights by limiting choices.

"I think people deserve a choice," said



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Donna Saskowski, Executive Director of Genesee Arc in New York, which is facing closure due to lost funding. “If they choose to be out in the community, that’s their choice. If they choose to be in the work center, I think they should also have that opportunity. If we eliminate the workshop, they no longer have a choice. Why can’t they have both?”

## A NEW VISION FOR PEOPLE WITH DISABILITIES: RESPECTING DIVERSITY AND CHOICE

In an effort to correct for past sins, the disability community has over-corrected. Just as there was nothing person-centered about placing individuals in overcrowded

institutions decades ago, there is also nothing person-centered about policies which support forcing all individuals to accept services and supports in small, “community-based” settings.

Both extremes neglect the need for person-centered supports in an unreasonable, and potentially dangerous, quest for “sameness.” The human condition is not that convenient. Equitable – providing individualized care and employment options – does not mean equal. People with disabilities have vastly different needs, requiring vastly different supports across the continuum. Choices will be different. The provision of care and related costs of

care must necessarily vary and be responsive to varying needs.

People with disabilities should not have to endure a different standard of community than other populations and society in general. Rights should be individualized, respectful of diverse conditions, and inclusive of the entire disability population.

In this spirit, VOR presents the following “Key Principles in Support of Ensuring the Rights and Opportunities for All People with Disabilities”. We call on the broader community of advocates to support and promote these principles.

Embrace diversity. Embrace choice. •



## KEY PRINCIPLES IN SUPPORT OF ENSURING THE RIGHTS AND OPPORTUNITIES FOR ALL PEOPLE WITH DISABILITIES

### GENERAL PRINCIPLES

■ “Individuals with disabilities” describes a widely diverse group of people, ranging from people with mild physical and/or intellectual disabilities to those with profound and/or severe intellectual disabilities, along with medical or behavioral disabilities.

■ “Individuals with developmental disabilities and their families are the primary decision-makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision-making roles in policies and programs that affect the lives of such individuals and their families.” DD Act, 42 U.S.C. 15001(c)(3)(2000).

■ Most individuals with disabilities are capable of living just like people without disabilities and should have the opportunity to do so. These individuals with disabilities should have control over their own day, including which job or educational or leisure activities they pursue, and where and how

they live, with any necessary supports.

■ Support for full community integration of most individuals with disabilities should not be interpreted to deprive individuals with profound intellectual and developmental disabilities (I/DD) or other serious I/DD and medical and/or behavioral disabilities from assurances of proper care of their health and safety needs, and individuals with disabilities should not be forced to accept services or participate in activities they do not wish to accept. As Justice Ginsburg wrote in the Olmstead decision, “Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing that, on a case by case basis, that setting may be in an institution.” (emphasis added)

### CHOICE

■ Individuals with disabilities and, where appointed by a court, their legal guardians, should have the opportunity to make informed choices among all legally available options. They must have full and accurate information about their options,

including what services and financial supports are available.

### EMPLOYMENT

■ Most individuals with disabilities should have the opportunity to be employed in regular workplaces. Most individuals with disabilities can be employed and earn the same wages as people without disabilities. When needed, individuals with disabilities should have access to supported or sheltered employment, or other day activities, to ensure fulfilling and productive experiences.

### HOUSING

■ Individuals with disabilities have the right to choose where to live from an array of residential options.

■ Most individuals with disabilities can live in their own homes with supports and they should get to decide where they live, with whom they live, when and what they eat, who visits and when, etc.

■ These choices for most individuals with disabilities should not deprive individuals with pro-

found I/DD or other serious I/DD and medical and/or behavioral disabilities from the right to live in congregate arrangements, multi-unit buildings or complexes that cater to specific needs, according to individual choice and need.

### PUBLIC FUNDING

■ Government funding for services should support implementation of these principles to assure a full array of residential and service options to accommodate the diverse needs and preferences of the disabled population. Financing for long-term services and supports must be responsive to the needs of all individuals with disabilities, recognizing that the cost to care for individuals must necessarily vary and be responsive to varying needs.

### TELL US WHAT YOU THINK!

Do you support these principles? VOR welcomes your comments.

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