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Meet VOR: An organization that refuses to redefine individual choice

By Tamie Hopp VOR Director of Government Relations & Advocacy

I am delighted to have this opportunity to introduce you to VOR, an organization that is really like none other.

VOR is a national, nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities.

We are the only national organization that has not redefined terms that other disability advocates have hijacked, like "choice," "community," and "self-advocacy."

Do self-advocates really speak for you?

For 35 years, VOR has remained true to the families we represent by putting their seasoned insights and perspectives first. To us and them, "choice" really means choice. Our advocacy is driven and guided by an undeniable truth: Families know best.

To get to know VOR even better, we suggest that you visit our website, at www.vor.net, and follow us on Facebook and Twitter.

You will find VOR unique and refreshing in this day and age of advocacy. We respect individual differences, and reject "broad brush" policies that apply to most individuals with disabilities, but not all. In our view, such an "all or nothing" approach is not person-centered or individualized and imposes an ideology on the most disabled members of our society and places them at risk.

VOR's advocacy – our walk to support our talk – is carried out at the state and federal levels by an army of members and volunteers, the vast majority of whom have family members with profound cognitive disabilities.

In state houses, court rooms, congress and the media, we are doing all we can to help change the conversation away from ideological notions of what is best for all people with developmental disabilities, to what each individual needs. We challenge laws, seek reforms and help families.

VOR demands realistic answers to the questions that concern families of individuals with intellectual and developmental disabilities in by working to ensure that the system is responsive to all needs, and challenging efforts at all levels, including our federal government, to eliminate specialized residential, vocation, and support services.

The need is significant. 3.5 million people with I/DD and autism are living with family caregivers (many who are elderly), there have been less than a quarter million out-o f -h o me residential opportunities funded in nearly 20 yearsⁱ, and 268,000 Americans with I/DD are on waiting lists for services.

Does it make sense to eliminate specialized service options for people with profound needs because of someone else's notion of "inclusion" and "community?"

A public exchange in EP Magazine (December 2013) between two advocates illustrates just how polarizing this debate has become – and how (alarmingly) the individual is ignored by federally- funded advocates.

Here, VOR's Geoff Dubrowsky, who is also a father and uncle to three family members on the spectrum, and Alison Lozano, the Executive Director of the federally-funded New Jersey Developmental Disabilities Council, offer their perspective of "diversity" based on individual need and choice:

<u>Alison Lozano:</u> "Everyone must live alongside everyone else in a regular neighborhood, enjoying their community to their fullest extent. This is what is called diversity."

Geoff Dubrowsky: "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 and college dormitories; and others choose to live in retirement or gated communities. Like the rest 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's 'regular.'"

VOR's vision of the world puts individuals and their families in the driver's seat, not federally-funded advocates or even "self"-advocates that attempt to speak for you and your family.

VOR is 100% privately –funded, supported entirely by our members, primarily families like you.

We invite you to learn more about VOR at www.vor.net.

The more families we have speaking up in support of individual rights, family rights and common sense, the more successful we will be.

ⁱ http://www.stateofthestates.org/documents/UnitedStates.pdf