

May 7, 2015

The Honorable Dave Burke, Chair
Senate Medicaid Committee
1 Capitol Square, Ground Floor
Columbus, Ohio 43215

Sent by email: sd26@ohiosenate.gov

Re: Support for DD Bill of Rights Amendments

Dear Chairman Burke,

VOR strongly supports Section 5123.62 of HB 64, which proposes changes to strengthen the Developmental Disabilities (DD) Bill of Rights language.

VOR is a national nonprofit organization advocating for high quality care and human rights for people with intellectual and developmental disabilities. We expressly support the right of individuals and their families to be primary decision-makers with regard to services, supports and policies.

We are aware of a letter from Advocacy United that opposes the proposed changes to the DD Bill of Rights. Advocacy United, a self-advocacy organization, claims support from other organizations, including but not limited to Disability Rights Ohio, The Arc of Ohio, and the Ohio Developmental Disabilities Council.

The proposed changes to the DD Bill of Rights do *not* take away the right of individuals with intellectual disabilities to self-advocate and make their own decisions. We support the right of Chairwoman Shari Cooper and Secretary Renee Woods, who signed the Advocacy United letter, to make decisions on their own behalf. As their letter indicates, many individuals with intellectual disabilities are capable of, and wish to, make their own decisions.

However, we strongly object to Advocacy United, Disability Rights Ohio, or any organization speaking on behalf of *all* people with intellectual disabilities. There is a vast spectrum of needs and abilities across the disability continuum. Some individuals with profound disabilities will require the support of families and legal guardians in making care decisions.

Recent initiatives in Ohio speak to the urgent need to expressly recognize the right of some individuals to benefit from decision-making support from their family and legal guardians. Policies in the Executive Budget, which would force the closure of many Intermediate Care Facilities (ICF) and replace facility-based day services and sheltered workshops, was motivated by Disability Rights Ohio's threats. Likewise, the Department of Developmental

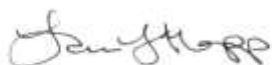
Disabilities' Strategic Planning Leadership Group recommended cuts to ICFs and workshops, thereby removing options for individuals with disabilities who require a higher level of care. The individuals and their families directly impacted by these proposals were not consulted. Nor did DRO, which claimed to represent thousands of disabled Ohioans, consult affected individuals or their families. On March 17, 2015, a family organization, Disability Advocacy Alliance, lodged nearly 19,000 petition signatures with the Ohio House of Representatives objecting to policies in the Executive Budget, making the point very clear that the proposals being supported by Disability Rights Ohio were not supported by the people they impacted.

Families of Ohioans with profound disabilities are grateful that the House of Representatives, after hearing from so many concerned individuals and their families, rejected much of the Executive Budget. However, the effort put forth by these families on behalf of their profoundly disabled loved ones should have been unnecessary. Families should have been included in development of the proposals in the first place. Families know best. As recognized by the Supreme Court in [Heller v. Doe](#), 509 U.S. 312 (1993), "close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered" in placement and care decisions."

Some organizations would rather be the voice for all individuals with disabilities, without regard to individual need and choice, and to the exclusion of families. This is exactly why the DD Bill of Rights needs language recognizing the unique, vital and primary role that individuals, and where necessary, their families and legal guardians play in decision-making

Please **approve Section 5123.62 of HB 64**, which proposes changes to strengthen the Developmental Disabilities (DD) Bill of Rights language.

Sincerely,



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cc:
The Honorable Scott Oelslager, Chairman of the Senate Finance Committee,
sd29@ohiosenate.gov

Caroline Lahrmann, Spokesperson, Disability Advocacy Alliance, calnwal@aol.com