VOR
A Voice Of Reason
Speaking out for people with
Intellectual & Developmental Disabilities

VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: (877) 399-4867
https//:www.vor.net

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
(646) 387-2267
hdwyer@vor.net

President
Joanne St. Amand
20 Sutton Place
Cranford, NJ 07016
(908) 272-0399
jrst.amand@verizon.net

An Open Letter to the President
&
The President's Committee for People with Intellectual Disabilities (PCPID)

President Joseph R. Biden
White House Domestic Policy Office, Director of Disability Policy Rachel Patterson
Secretary of the U.S. Department of Health and Human Service Xavier Becerra
Members of the President's Committee for People with Intellectual Disabilities, Jim Brett, Chair

Dear President Biden and all concerned,

This letter is written on behalf of the hundreds of thousands of individuals with intellectual disabilities and autism who are unable to speak for themselves, who rely on parents and siblings to speak for them. Many are non-verbal, while many others have speech but lack the capacity to make informed decisions that would ensure their own health and safety.

We comprise a large and varied cohort of individuals and families, and our voices need to be heard. We include the families of people who live their best lives in intermediate care facilities, who rely on high quality care that includes 24/7 nursing and active treatment, who are constantly threatened with closure of these facilities by legal actions from the DOJ, P&A, or the whims of a governor or state legislature. We include the families of people who have been denied care by group home providers who do not offer services and supports appropriate to our needs, or are unable or unwilling to deal with our loved ones' episodes of aggressive behavior. We include people who have been dual diagnosed with autism and severe mental illnesses, and reside in psychiatric hospitals because there are no services that meet our needs. We include family caregivers who want our loved ones at home with us, who cannot access the resources we have been promised, because of the shortage of Direct Support Professionals (DSPs) and the reluctance of many to deal with the challenges our loved ones pose. We include family caregivers who provided care at home because we cannot find appropriate placements for our loved ones in group homes or intermediate care facilities. We include people who have developed medical conditions as we have aged, and have been moved out of group homes that can no longer provide for our needs and have been moved into nursing homes. We include people who reside in prisons, because we were not provided with services that met our needs, and became a danger to society. We are individuals who have, for any number of reasons, not been granted the services that *we* need to live *our* best lives.

We have often been excluded from our own community. Many of those who seek inclusion in the community of non-disabled individuals often exclude those of us whose need services and supports not provided in community settings. People with mild to moderate autism, and the organizations that support them, opposed including the words "severe" or "profound" in the Autism CARES Act or the revised DSM-V. The last assembly of the PCPID considered phasing out sheltered workshops and 14(c) certificates, while excluding from its membership the families of those who benefit from working in those settings.

We fully support including people with I/DD and autism in all decisions made about their well-being. But "Nothing about us without us" has never included *us*, or our family members who speak for us, or the DSPs who work with us and care for us. "Nothing about us without us" does not allow those who know us best, who love us most, and who live every day fighting for us, to speak on our behalf.

Our voices need to be heard by the President, too. Any report from President's Committee for People with Intellectual Disabilities *must include us*, and our families and DSPs, so that the President is able to make fully informed decisions about programs that benefit ***all*** people with intellectual disabilities and autism.