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VOR – A Voice Of Reason - is a national non-profit organization run by and for families of people with intellectual and developmental disabilities (I/DD) and autism. Founded over 40 years ago, our mission has always been to help families access the best resources for their loved ones. VOR believes that in order to meet the individual needs of every member of this diverse population a full array of options and opportunities must be available for each person's medical, intellectual, emotional, and behavioral challenges.

We are concerned that the agenda announced by the President's Committee on People with Intellectual Disabilities does not include many of VOR's families with loved ones who are on the severe/profound end of the I/DD and autism spectrums. They include high acuity individuals whose needs are best met in intermediate care facilities (ICFs), those who have lived in "community" group home settings and not had their needs properly addressed, those with complex medical conditions who require services not affordably provided in group homes, those living at home with parental caregivers who cannot get the outside services that they have been allocated due to the shortage of direct support professionals (DSPs), and those who cannot be accommodated by employers offering Competitive Integrated Employment who make the informed choice to take advantage of opportunities to work in facility-based environments with commensurate wages under Section 14(c) of the Fair Labor and Standards Act.

Becoming the parent of a child with I/DD or autism involves a lifetime of difficult decisions. For the parents of people with more severe disabilities, the choices are often more difficult, the available options are fewer, and there may be little support and understanding from government agencies or from other disability advocates who have not walked their path. More often than not, those agencies and advocates work to further limit or phase out the options available to those with more severe challenges.

It shouldn't be this way.

The President's Committee on People with Intellectual Disabilities (PCPID) should include *all* people with intellectual disabilities, and not focus only on the aspirations of those individuals who best integrate into the community of non-disabled individuals. The PCPID should assure that the most vulnerable members of the ID/A community are not being overlooked, and further marginalized, by those who are directing disability policy.

PCPID's agenda for its upcoming meeting clearly states that one of the functions of this committee is to "provide advice to the President and the Secretary of Health and Human Services to promote full participation of people with intellectual disabilities in their communities". There is no mention in this mandate of addressing the needs of individuals with I/DD or severe autism.

To be clear, we support several aspects of this agenda, and we most certainly support any actions that will help any individuals with I/DD and autism, but we take a somewhat different view on this committee's exclusion of the most vulnerable members of the I/DD and autism communities.

(A) Expanding educational opportunities – We support this, of course, but are concerned about restraints and isolation rooms that hurt those individuals whose needs are not addressed by the educational systems that are supposed to help them.

(B) Promoting housing opportunities – Again, we support programs that help people be more independent and integrate with non-disabled people in their communities. But we feel that the Settings Rule imposes restrictions on where people can live based on the idea that they must live and interact with non-disabled individuals, whether that is their choice or not.

(C) Expanding opportunities for competitive integrated employment – We support competitive integrated employment (CIE) for those who can be accommodated in such programs. We oppose any legislation that would provide funding for CIE while phasing out and eliminating 14(c) programs. The President's Committee for People with Intellectual Disabilities should not be working against over 100,000 people with Intellectual Disabilities by taking away opportunities that benefit them.

(D) Improving accessible transportation options – VOR supports this and urges PCPID to also support programs to safely evacuate people with I/DD during natural disasters or other large-scale emergency situations.

(E) Protecting rights and preventing abuse – We ask that this committee, and its overseers at the Administration for Community Living, mandate that Protection and Advocacy agencies use the resources granted them by the federal government and administered by the ACL, to investigate abuse and neglect throughout the entire DD system, and stop wasting taxpayer dollars by attempting to close federally funded and CMS-certified ICFs. Abuse happens in all settings, large and small, and P&A's across the country have not been performing unannounced inspections to group home providers as they do with ICFs. By providing prior notification to group homes, the likelihood of their being able to uncover violations and recognize signs that show potential for abuse of the residents.

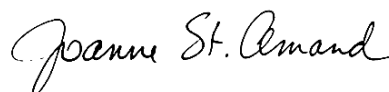
(F) Increasing access to assistive and universally designed technologies – VOR agrees.

When the time comes for this committee to "provide advice to the President and the Secretary of Health and Human Services to help advance racial equity and support for people with intellectual disabilities within underserved communities" we urge you to include policies for those people with I/DD and autism who are not served by Home- and Community-Based Services, as they are also members of this community and deserve equal representation from the President's Committee for People with Intellectual Disabilities.

Thank you for your time and consideration.



Hugo Dwyer – Executive Director



Joanne St. Amand – President