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

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President's Committee for People with Intellectual Disabilities
James T. Brett, Chair
Public Testimony for July 28th Meeting

July 25, 2022

Dear Chair Brett, Citizen Members, Ex-Officio Members, and representatives from the Administration for Community Living,

As the committee considers priorities for this coming term, I submit the suggestions below. The overall goal of these topics is to acknowledge the need for supporting a full continuum of care and creating a system that reflects the diversity of the individuals it serves. Individuals and families deserve choice, and the power to make their own choices from a wide variety of high-quality settings.

The availability of Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID or ICFs) has eroded over the past four decades. While some of this has been appropriate, addressing the choices of those with I/DD who prefer to live in smaller settings and integrate into their communities, much of this erosion has been ideologically driven and has infringed on the rights of many who have chosen ICFs, or would have chosen ICFs if there were placements available. This "One-size-fits-all" approach has notably marginalized those with the most severe intellectual disabilities, violent or self-injurious behaviors, profound autism, and those whose combination of challenges include complex medical conditions. It's time we re-assess the system we have created and the direction that we have taken. For many families, the aspirations of those who wish to live in integrated settings have been given policy and appropriations priority over the existential needs other individuals who require higher levels of care. **As a community with shared concerns, we should be united in ensuring a full continuum of care and offering a diverse palette of services equal to the diversity of this population and the range of their needs.**

We *need* large congregate care facilities. *Good* ones. Larger facilities can take advantage of the economies of scale to provide the necessary services for those with exceptional needs, including 24-hour nursing, active treatment, pica-specific housing, on-site medical and psychiatric services, or behavioral therapy. The comments we all hear about people being forced into institutional settings make a good sound bite, but the fact is that people who might benefit from ICF-level of care are not allowed admission to ICFs. Their only option is the HCBS system, and when that system fails to meet their needs, they are forced into inappropriate institutional settings - psychiatric hospitals, nursing homes, and forensic facilities. Because of closed admissions and the dwindling availability of *good* institutions, such as ICFs/IDD, many individuals end up in *bad* institutions that are inappropriate to their treatment and care.

The same one-sided ideology is evident in employment opportunities, where the aspirations of those who seek competitive integrated employment have received higher priority than providing opportunities for those who wish to work, but are unlikely to be accommodated by businesses that offer employment in competitive integrated settings. There is no need to eliminate well-regulated, *voluntary* employment programs that pay commensurate wages to one cohort of individuals in order to create competitive integrated opportunities for another. We should be vigorously supporting *all* opportunities.

This imbalance extends to the funding for these services. The American Rescue Plan Act (ARPA), the intent of which was to address the effect that the first phase of the Covid pandemic had had on individuals, educational institutions, and businesses of all sizes, only provided funding for one silo of Medicaid's long-term care services and supports: Home and Community-Based Services (HCBS). People in ICFs, Skilled Nursing Facilities, and other non-HCBS settings suffered equally, if not more, under Covid-19. They were overlooked by ARPA. This exclusion continued in the proposed funding of I/DD services in the Better Care Better Jobs Act and the Build Back Better Act.

We need to end this ideological imbalance, and support ***all*** individuals with I/DD and their needs, their aspirations, their treatment and care and provide them with whatever will help them to live their best lives, instead of focusing on the type of setting or funding stream from which they receive their services.

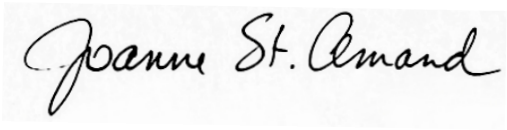
That said, the biggest issue facing all of us is the lack of Direct Support Professionals. I would suggest that this Committee address this issue during its term. And that the scope of this project not be limited to DSPs working in HCBS settings, but in ***all*** settings. By supporting increased wages and training for DSPs only in HCBS settings, we will make it impossible to fully staff other settings - those that attend to the most vulnerable, highest-needs individuals. The DSP crisis exists in all settings, and will likely impact those with the highest needs regardless of the setting in which they may reside.

I would further suggest that we not dilute this matter by including housing in the scope of this committee's effort. While important, the real crisis is the need to effectively rebuild the workforce. Settings are closing due to providers' inability to find and retain well-trained staff, provide wages that are commensurate with other health care professionals, and are appropriate to the requirements of their job.

If we rebuild the workforce, housing will follow.

If, however, this committee does choose to address housing, I hope that they will recognize the need to support building new ICFs/IID, as well as only supporting HCBS housing. If the committee supports the needs of all I/DD individuals, your priorities, actions, and endorsements should reflect the continuum of care settings to protect choice and quality. We need to ensure that people may live in the setting that best suits their needs.

On behalf of the families of VOR - A Voice of Reason,



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