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U.S. Department of Health and Human Services
Office for Civil Rights
Hubert H. Humphrey Building
Room 509F
200 Independence Avenue SW
Washington, D.C. 20201

Re: RIN 0945-AA15

**Proposed new implementing regulations on Section 504 of the Rehabilitation Act of 1973:
Non-discrimination on the basis of disability in Health and Human Services programs or activities.**

VOR – A Voice of Reason advocates for a full continuum of care and a full array of residential services and employment opportunities for all people with intellectual and developmental disabilities and/or autism. We would like to remind HHS of the broad diversity that characterizes the individuals who make up this population, from those who need some assistance to function in society to those who cannot survive without 24 hour around-the-clock assistance.

For the past 25 years, HHS has pursued “inclusion for all” policies that VOR believes have left behind the most disadvantaged members of this community. Before you take another step to dismantle more of these programs, we would urge you to review the purposes of the ADA, the *Olmstead* decision and the real-world effects on the most vulnerable population that we believe has been demonstrably hurt and even died as a result of these policies. We urge you not to just count the number of large facilities closed and people moved into the community, but to assess whether their needs are being met, whether there are sufficient well-trained staff and the overall the quality of their lives, including the frequency of abuse and neglect and the mortality rates relative to their former homes.

The ADA recognized the harm that our society had done by institutionalizing people who were “different” and called for giving them opportunities to participate in mainstream activities. *Olmstead* properly implemented that policy by permitting two individuals who wished to leave an institution and move into a less restrictive environment to do so, recognizing that institutional care was, by definition, segregated care. At the same time, Justice Ginsburg recognized that the I/DD population varied widely and that, for some people, an institution was the least restrictive environment.

Since enactment of the ADA, government policy has helped thousands of people who were capable of living and prospering in the broader community to leave institutions and lead a more productive and filling life. The DD System overseen by HHS has played a major role s in helping people who seek care in less restrictive environments to transition into Home- and Community-Based Services (HCBS) settings or receive more at-home or own-home supplemental services. We applaud the success of these programs. At the same time, we have been concerned that this movement has ignored the reality that Justice Ginsburg recognized that some people can benefit most from institutional care and that ideological blinders have eroded another key component of the DD System – intermediate care facilities for people with intellectual disabilities (ICF or ICF/IID).

Part of the premise for pursuing the closure of ICFs has been the usually unspoken view that parents who choose ICF care for their loved ones are not acting in their best interest. Nothing could be farther from the truth. Being the parent or sibling of a child with severe or profound intellectual disability or autism

presents a lifetime of tremendous challenges. Aside from the daily challenges posed by the child her/himself, one of the most difficult challenges is navigating the DD System. Parents and guardians try to make informed choices from a limited set of imperfect options. Most families' first choice is to have their child live at home. As the child ages and new challenges emerge, the parents have to re-assess those options, often choosing a small privately operated group home. If and when the group home system fails to meet their child's needs, they usually seek a higher level of care in a larger congregate setting. Unfortunately, our system usually makes this difficult decision even more difficult to realize. Federal and state policies favoring HCBS care over the years have reduced the number of available beds in ICFs and created a two-tiered system, favoring HCBS funding and decreasing funding for the ICF system. While many proponents of HCBS' inclusionary policies see this as progress, the families that rely on ICF services feel they have been victims of discrimination by their own community and by the very systems that have been put in place to serve them.

ICFs are not for everyone. *Most* people *do* benefit from some form of HCBS service. But not everyone. Larger congregate care facilities offer an economy of scale, allowing them to have 24/7 nursing, doctors on campus Monday – Friday and on call nights and weekends, dental clinics, psychiatric services and behavioral specialists, physical therapy, music therapy, swimming, and other services and amenities, most of which cannot be offered in a small group home. ICFs are more highly regulated by CMS and certification is far tougher than it is for HCBS services. Also, ICFs are required to offer active treatment, which may or may not be offered in group homes, but is not required. For people whose existential needs exceed their desire for acceptance by the non-disabled community, ICFs are essential.

Section 504 prohibits discriminatory acts in health care and human services, including ***denying qualified individuals the opportunity to participate in or benefit from federally funded programs and services.*** ICFs are federally approved, federally funded residential facilities. Many states have closed admission to these facilities, or ceased to create new opportunities to receive care in these facilities in favor of moving individuals to HCBS services. We contend that Section 504 must protect the right to care in ICF settings as well as in HCBS settings.

This discrimination has become accepted by all but those who need this level of care. The governors of several states have closed ICFs based on the biases of those who portray the ID/A population as a monolithic group that always benefits from community living. Presidential administrations have endorsed this ideology. The Department of Justice, too, has brought lawsuits, closing facilities for not meeting these arbitrary standards.

The bias in favor of HCBS care was memorialized on April 18, 2012, when the Administration on Developmental Disabilities and other agencies were combined into the Administration for Community Living (ACL). Over the past decade, ACL has pursued an ideology of “everyone does better in the community” that ignores the fact that many of those with severe and profound I/DD and autism cannot. As a result of this directive, ACL has funneled millions of dollars into state DD Councils and state Protection and Advocacy agencies (P&A). These agencies have targeted ICFs, launching far more on-site investigations in these facilities than in group home environments, and using federal funds to initiate class action suits aimed at closing ICFs (Illinois, *Ligas v. Maram*, and Ohio, *Ball v. Kasich* to name just two. In both of these cases, the court found for the families defending ICF care, but at a huge personal cost to the families involved).

In addition to funding the National Association of Councils on Developmental Disabilities (NACDD) and the National Disability Rights Network (NDRN), the ACL provides funding for the Association of University Centers on Disabilities (AUCD). The AUCD conducts studies on matters affecting people with I/DD and autism, but usually limits the topics of their studies to those which will point to successful outcomes of programs initiated by the ACL. They have not conducted studies on mortality rates of people who have been forced out of their ICF homes of thirty or forty years when state governors have acted, either independently or at the direction of the state P&A or DOJ lawsuits, to close these facilities. They

have not attempted to document the outcomes of people who have been forced out of sheltered workshops and 14(c) employment opportunities and wind up in day programs with no work, no pay, and no options, and forced into an even more segregated community with a cohort of more severely disabled individuals.

Discrimination against the neediest people with ID/A also applies to employment opportunities. Employment facilities licensed under provisions of Section 14(c) of the Fair Labor Standards Act, aka sheltered workshops, have been under attack by many of the same groups that advocate for the closure of ICFs. Without these programs, most of those who participate in them would be left without daytime activities as the reality is that they cannot perform to a level that warrants paying them the minimum wage. Ideological dogma cannot change reality. Despite the fact that these are voluntary programs, and the fact that they are enthusiastically approved by a vast majority of those who participate in them (97%), non-participants with high acuity, non-intellectual disabilities, federal and state agencies, and federal and state legislators have been calling for these programs to be phased out and eliminated. Furthermore, we would contend that the states that have ended their 14(c) programs have already committed discriminatory acts against people with intellectual disabilities and autism, by ***denying qualified individuals the opportunity to participate in or benefit from federally funded programs, services, or other benefits***. If we are indeed to rectify this discrimination, should we not insist that those states re-open access to 14(c) programs?

The normalization of these discriminatory policies by HHS also gives license to the Congress to enact legislation that further discriminates against the neediest component of the ID/A population. The continuing enactment of legislation that either increases funding for HCBS services only or establishes a favorable funding formula for those services instead of ICF services is yet another way that HHS is complicit in undermining services for those who need them the most. Advocating and supporting these discriminatory policies gut a federal program that remains on the books and provides valuable and often essential service. At the same time, it has not met its practical goals – to provide more money and better services for people who reside in HCBS facilities. It is past time for HHS to return to the basics of the ADA and *Olmstead* – to insure that individuals with ID can choose where they wish to live and to advocate for what is best for the individuals, as determined by them and their families and guardians, not by lawyers and professional advocates.

The Supreme Court's 1999 decision in *Olmstead* is often cited as a mandate for inclusion by self-advocates, well-endowed advocacy organizations, and government agencies. As indicated above, that is not what the decision says. *Olmstead* protects *choice* in its three-prong test and specifically acknowledges the need for "institutional" care, *i.e.* intermediate care facilities, in some circumstances. Justice Ruth Bader Ginsberg cited an amicus from VOR in her decision, stating, "*Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be in an institution.*"¹

The Court was very clear that *Olmstead* was not to be viewed as a one-dimensional "inclusion mandate", recognizing the need for States to maintain a range of facilities for the diverse needs of persons with developmental disabilities:

*"Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand."*²

*"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . Nor is there any federal requirement that community - based treatment be imposed on patients who do not desire it."*³

*"[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities [1] when the State's treatment professionals determine that such placement is appropriate, [2] the affected persons do not oppose such treatment, and [3] the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."*⁴

*"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. . . Some individuals . . . may need institutional care from time to time 'to stabilize acute psychiatric symptoms'. . . For other individuals, no placement outside the institution may ever be appropriate...for these persons, institutional settings are needed and must remain available."*⁵

To be clear, we understand that we are asking the very agencies that created these policies and discriminated against those with the most severe and profound levels of I/DD and autism to cease these discriminatory practices. But, before you move further down this path, we ask you to look at our families and our loved ones through our eyes for a few moments:

Having a child with a severe or profound intellectual disability or autism involves a lifetime of extremely difficult choices. Our families ask for your help and support in making the best choices, from a full range of high-quality options, not from a rigid ideology that does not comport with reality. We ask for this support from those in government who oversee the DD system and provide those services, and from the community of people with I/DD and autism and their families, who should be the first to empathize with our challenges and provide emotional support. It's time we end the discrimination against those with the most severe intellectual and developmental disabilities and autism. These ideals should be at the heart of any re-assessment of Section 504.

¹ Olmstead v. L.C., 527 U.S. 581, at 605

² *ibid*, at 597

³ *ibid*, at 601-602

⁴ *ibid*, at 607

⁵ *ibid*, at 604-605