



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

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012
(410) 757-1867
LarryInnis@aol.com

To: Department of Health and Human Services (HHS)
Office of the Assistant Secretary for Planning and Evaluation
Strategic Planning Team
Attn: Strategic Plan Comments

Re: HHS DRAFT Strategic Plan FY 2018 – 2022

Date: October 26, 2017

To Whom It May Concern:

Please accept these comments from VOR in response to the request for comments on the HHS Draft Strategic Plan FY 2018 – 2022. VOR is a national non-profit organization that advocates for high quality care and human rights for individuals with intellectual and developmental disabilities. VOR's members are parents, siblings and legal guardians of individuals with severe to profound intellectual disabilities, have severe behavioral problems or are medically fragile. Our concern is not only what is in HHS' Strategic Plan, but what is **not** in the plan. Our loved ones' lives depend on services and funding provided by HHS, and our loved ones are overlooked in this plan. When people with disabilities *are* mentioned, all people with all different types of disabilities are combined with the elderly and aging population, as if HHS believes all of these people have similar needs, and that the same solutions applicable to one of these groups can be applied to the problems of all other groups.

This is wrong.

Reading this document, two things are clear. First, this Strategic Plan has been written from the point of view of the system that provides services to Americans, not from the perspective of those who receive, and are dependent upon, those services. Second, it is clear that even though HHS is operating under a new administration, the agency is continuing the policies of the Obama Administration. Many of these policies were actually developed years earlier, in the Clinton era. After twenty-five years of failed policy, ever-growing waiting lists for services, Inspector Generals' reports of failure to report incidents of abuse and neglect in the application of the HCBS waiver system in multiple states, and the many documented cases of abuse, neglect, and death in community settings, HHS still operates as if this is the best system, that one-size-fits-all for this diverse population, and that intermediate care facilities (ICF's/IID) are not an essential component of a system designed to meet the needs of the extremely diverse, extremely fragile population of individuals with severe to profound intellectual disabilities.

Has HHS learned nothing in twenty-five years? The system is geared towards helping the most capable members of our community, those who can manage to live in settings that require less oversight in HCBS group homes, individual living units or family home care. Individuals with more severe intellectual disabilities, those who require a comprehensive program of supports and services through Active Treatment available only in an ICF/IID, are neglected in the strategic plan, and are consistently marginalized by the Department of Health and Human Services and its subdivisions in the Centers for Medicare and Medicaid Services (CMS) and the Administration for Community Living (ACL). It's time to correct the flaws that riddle this system.

GOAL 1: REFORM, STRENGTHEN, AND MODERNIZE THE NATION'S HEALTH CARE SYSTEM

Our concern with Goal 1 is that nowhere is there any mention of Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF's/IID) as part of the nation's health care system, despite the fact that the federal law that authorizes them has not been repealed. These private and public facilities, are crucial to the care of individuals with severe and profound intellectual disabilities, and offer 24-hour care to those individuals with one or more contributing medical, psychiatric, and behavioral conditions. According to Medicaid, *"ICF's/IID provide active treatment (AT), a continuous, aggressive, and consistent implementation of a program of specialized and generic training, treatment, and health or related services, directed toward helping the enrollee function with as much self-determination and independence as possible. ICF/IID is the most comprehensive benefit in Medicaid."* (<https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html>)

(Lines 277 – 279) “Expand the engagement of patients, families, and other caregivers in developing and implementing programs that improve the quality of care and increase access to services available to them.”

This goal should be implemented to pertain to the severely/profoundly intellectually disabled, but families of severely intellectually disabled individuals are not being informed of the availability of ICF's in their states, and states have discontinued or are closing these services.

Lines 280 – 282 “Promote the development, implementation, and use of experience and outcome measures, including patient-reported data and price transparency data, as appropriate, for use in quality reporting”

This sounds good on paper, but has little application to the needs of our families and their loved ones. New methods of measuring the level of an individual's disability, such as SIS evaluations, are poor substitutes for assessments by qualified professionals and direct support professionals who work with our family members on a daily basis. Cost comparisons between ICF/IID services are often skewed to

include services at ICF's that are not included in the cost evaluations of HCBS waiver settings. Also, the level of incident reporting in HCBS waiver settings is - by design - less robust than ICF reporting because HCBS settings omit different types of incidents which ICF/IID facilities are required to report.

Line 380: “Reduce disparities in access to health care”

Lines 386 – 387: *“Support research to provide evidence on how to ensure access to affordable, physical, oral, vision, behavioral, and mental health insurance coverage for children and adults”*

Lines 394 – 396: *“Remove barriers to inclusion and accessibility for people with disabilities in public health programs (e.g., communication, physical environment, workforce competencies for public health and healthcare professionals)”*

HHS should remove inclusion when it becomes a barrier to people with disabilities receiving high quality care. Intermediate Care Facilities offer high quality dental, psychiatric, and other health-related services that are tailored to competently serve intellectually disabled individuals. Unfortunately, CMS has mandates that prevent people in HCBS waiver settings from participating and benefiting from these services, claiming these facilities are not sufficiently integrated with the non-disabled population. In so doing, CMS is prioritizing inclusion over quality care and denying available services to individuals who need them. Intellectually disabled individuals living in community settings often have difficulty in finding dentists who can see them, especially those individuals who require anesthesia for a routine cleaning.

HHS would benefit from removing inclusion as a barrier to health care services for the intellectually disabled.

GOAL 2: “PROTECT THE HEALTH OF AMERICANS WHERE THEY LIVE, LEARN, WORK, AND PLAY”

While there is (laudably) a strong focus in this goal on how to best address America's opioid crisis, there is very little attention paid to people with disabilities. People with disabilities, including people with intellectual disabilities, are Americans. If HHS is going to protect the health of Americans where they live, learn, work, and play, the agency is obligated to acknowledge that the needs of some populations differ from those of the majority of Americans and even the majority of people with disabilities, and create protections specifically designed to benefit even the minority population of individuals in need.

The two sections of interest in this goal are both given lip-service by HHS, but are rarely executed in a manner that benefits people with severe intellectual disabilities:

Lines 677 – 678: “Improve access to high-quality care and treatment for mental and substance use disorders: Support the integration of the full continuum of behavioral health care and primary care and medical systems, and increase the capacity of the specialty behavioral health systems to ensure that the physical health needs of the people they serve are met.”

For the intellectually disabled, the full continuum of care and medical systems must include access to (ICFs/IID). Every other part of this strategic plan either overlooks the above statement or attempts to negate it. We urge HHS to stand by this statement, to apply the principles therein to our population as well as to mental and substance abuse disorders, and to support a full continuum of care for the intellectually disabled that includes ICFs nationwide. Requests for admission to ICF/IID facilities should not be discouraged and should be made in “*accordance with state variation of the ICF/IID level of care criteria and the requirement of the states to provide access [to ICF's] to individuals who meet the coverage criteria defined in federal law and regulation.*”

(<https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html>)

Lines 696 – 697: “Ensure that individual rights are protected including addressing abuse and neglect, parity, Olmstead, Americans with Disabilities Act, and other protections”

VOR supports the full reading of the Olmstead decision, which specifically includes “institutions” as part of the full continuum of care and supports the rights of families or guardians to choose a larger congregate care facility as appropriate to the needs of the individual:

“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.”

- *Olmstead v. L.C.* 527 U.S. 581, 601-602 1999

[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, [3] and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.”

- *Olmstead v. L.C.* 527 U.S. 581, 601-602 1999

The language in the Strategic Plan once again interprets Olmstead only as a decision in favor of moving individuals into HCBS waiver settings, willfully ignores the provisions that protect the right to choose an ICF/IID, and violates the intent of the ADA and Olmstead.

GOAL 3: STRENGTHEN THE ECONOMIC AND SOCIAL WELL-BEING OF AMERICANS ACROSS THE LIFESPAN

The goals herein may be appropriate to some but not to others whose health and happiness are not dependent on integration and inclusion. For these individuals, integration and inclusion are not the primary goals. Medical attention, quality direct support, safety, and comfort are far more important to their well-being than being in the presence of non-disabled individuals. However, Medicaid does report that *"Many ICF/ID residents work in the community, with supports, or participate in vocational or other activities outside of the residence, and engage in community interests of their choice. These activities are collectively often referred to as day programs. The ICF/ID is responsible for all activities, including day programs, because the concept of AT (active treatment) is that all aspects of support and service to the individual are coordinated towards specific individualized goals in the IPP (individual program plan)."* (<https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html>) The Strategic Plan again fails to acknowledge our family members and their needs.

Throughout the **Goal 3** section of the Strategic Plan, the emphasis on transitioning from institutions to the community neglects the diverse and changing needs of individuals. What about the people who could benefit from transition from inappropriate, ill accommodating, or otherwise risky waiver settings into ICF/IID services? Intellectually disabled individuals who fail to adapt to HCBS environments should be given the opportunity to benefit from the comprehensive services and supports an ICF/IID is federally mandated to provide. People with intellectual disabilities who develop further medical complications with age find that the group home or other HCBS waiver settings where they may have lived for years is no longer capable of supporting all of their needs. In most cases, these individuals are sent to inappropriate, ill accommodating, and otherwise risky facilities like hospital wards, nursing homes, or psychiatric facilities because HHS refuses to support ICF/IID settings.

Line 925: *"Identify and disseminate evidence-based practices to reduce injuries and violence"*

Line 955 – 956: *"Collect, analyze, and report national data on incidence and consequences of injury and violence"*

HHS is aware of injuries and violence in community-based settings. The Inspector General of the Department of Health and Human Services has issued reports in several states in recent years that show the under-reporting of incidents in HCBS waiver settings. Over the last five years, the New York Times, The Chicago Tribune, The Washington Post, the Augusta Chronicle, and the Atlanta Journal-Constitution have all run series documenting abuse, neglect, and deaths in community settings due to lack of oversight from state monitoring agencies, lack of training of caregivers, and lack of background checks in hiring caregivers. This indicates a nationwide trend, not isolated incidents. This body of evidence already exists. The problem is not that HHS needs to collect more evidence, but that HHS needs to act on this evidence.

Line 1004: *“Support Parents, Guardians, and Caregivers.*

Families and guardians are not given a full range of choice regarding residential care settings to include the ICF/IID option which provides the most comprehensive care (supports and services) available under any payment source. That is the support we need. When you take away options, like closing ICFs/IID, you are not supporting parents, guardians or caregivers.

Line 1008: *“Support efforts, including through faith-based and community organizations...”*

There are over twenty-five references to faith-based organizations in this draft of HHS’s Strategic Plan. With rare exceptions, faith-based and community organizations do not work with severely intellectually disabled individuals. They generally provide services for individuals with higher intellectual competency levels.

HHS ascribes to faith-based organizations as part of the safety net, to be relied upon to provide services. This is dangerous. HHS is the safety net. People who need services must be able to rely on HHS for those services. Faith-based organizations may indeed augment those services, and provide additional services not covered by HHS, but they cannot and should not be counted on to always be there. The role of faith-based or other community organizations must be incidental in nature to the needs and care of individuals.

Line 1067: *“Develop age- and dementia-friendly livable communities to improve quality of life for older adults, families, caregivers, people with disabilities, and the larger community”*

VOR supports intentional communities as part of the continuum of care. We believe that they demonstrate the value of a non-integrated option for people who are more comfortable being among their peers or would obtain tangible benefits from living together. The elderly often prefer to live in protected environments that are tailored to their needs, their abilities, and their tastes. The deaf community thrives in a language-rich environment where they can communicate with others through American Sign Language. For them, integration with the non-deaf community is isolating, not integrating, as they are unable to communicate with those who do not speak their language.

Integration and inclusion should be viewed as options, not mandates. These constructs are best served via subjective (individual) interpretation. If HHS’s Strategic Plan allows for this form of non-integrated livable community for older adults, there should also be support for ICF/IID as an option for those who prefer this form of residential care and service. Demonstration of integration and inclusion through supports, services and programs should not be predicated on a generic pathway, rather a person-centered, choice-oriented delivery system would best adhere to the tenets of Olmstead.

Line 1078: “Support improved care transitions and care coordination

Lines 1079 – 1082: “Promote collaboration among federal, state, local, and private sector partners, including faith-based and community organizations, that serve older adults, people with disabilities, and their families and caregivers to improve access to a full range of healthcare services, and home and community-based services”

This entire section of the plan disregards the needs of those who cannot successfully transition to home and community-based settings, or those who choose not to. HHS refers to giving people with disabilities access to “a full range of healthcare services” without once mentioning ICF/IID services in this Strategic Plan. That is not a full range of services, and it defies the letter of Olmstead in pointing out the need for “institutions” as an essential part of the continuum of care.

Lines 1088 - 1089 “Improve quality and availability of long-term services and supports, including home and community-based services (HCBS)”

Again, HHS refuses to incorporate ICF/IID settings in this plan. What ‘long-term services and supports’ are being referenced here?

Line 1126 – “Strengthen the workforce”

VOR agrees with the provisions in this section, but would add to it.

VOR believes that in order to attract and maintain a dedicated and quality-motivated workforce, the occupation of long-term caregiver should be treated as a career, with rewards for education and training and performance-based incentives. Higher wages and benefits are essential elements toward improving employee retention.

We also believe that strengthening the workforce means getting rid of the bad apples. Background checks vary from state to state. In some states, background checks are in-state only, and are superficial, at best. A person disqualified from working in one state may move to one of these less-rigorous states and be allowed to work as a caregiver there. In many states, there is only an initial background check, with no follow ups. Once having passed the initial background check, the caregiver may be subsequently charged with offenses or activities that would have prevented their hiring, without these incidents altering their employment status. There are states where the background check must be paid for by the applicant, which may eliminate otherwise qualified persons from applying if - at the time - they are unable to afford this pre-employment condition.

VOR proposes that HHS use its mandate to require all states to pay for background checks using the FBI's Integrated Automated Fingerprint Identification System (IAFIS) when hiring long-term caregivers and that follow-up checks should be required at regular intervals.

The combination of providing incentives to attract good workers, providing rewards to keep these good workers, and improving monitoring and background checks to remove the poor workers is the best way to strengthen the workforce.

GOAL 4: FOSTER SOUND, SUSTAINED ADVANCES IN THE SCIENCES

VOR agrees with the plan as written in Goal 4.

GOAL 5: PROMOTE EFFECTIVE AND EFFICIENT MANAGEMENT AND STEWARDSHIP

Most of the proposed strategies under this section of the plan have been discussed in detail above, especially those regarding ways to improve the workforce.

Lines 1501 – 1507: “Manage the costs associated with governmental imposition of private expenditures through implementation of Executive Order 13771 of January 30, 2017, Reducing Regulation and Controlling Regulatory Costs, by ensuring that, consistent with the Administrative Procedure Act and as informed by the terms of the Executive Order and associated guidance, for every one new regulation issued, at least two prior regulations are identified for elimination, and the cost of planned regulations are managed through a budgeting process”

VOR is concerned with the implications of this Executive Order, as the two to one ratio is arbitrary and assumes that every department of our government is filled with unnecessary and harmful regulations. Nonetheless, that is the law, and there are some unnecessary and harmful regulations in HHS and CMS. We would suggest that HHS begin by removing restrictions on admissions to ICFs/IID, and those regulations that mandate integration or inclusion instead of promoting these values as options or goals for those who desire and are best suited to integration.

CLOSING COMMENTS

In conclusion, we feel that the FY 2018-2022 Strategic Plan is an opportunity for HHS to assess its direction regarding the intellectually disabled, especially the more severely disabled minority within this minority population. In the current draft, there is no mention of our loved ones. We hope that this document will inspire HHS to move beyond the one-size-fits-all doctrine that defined the previous administrations' approach, and to create a true, full, continuum of care.

We believe that the aging of individuals with IDD is a concern best addressed by strengthening the ICF/IID component of the healthcare system and reopening ICFs/IID to new admissions. We also believe that these facilities provide cost savings to the system by providing economies of scale when operating at optimal capacity.

We believe integration into the non-disabled community should be a goal, not a requirement. HHS should acknowledge that for some, the most integrated environment may be an Intermediate Care Facility, as stated in Olmstead.

We hope that HHS will use the recommendations we have put forth to improve the quality of the workforce of long-term caregivers and Direct Support Professionals for the intellectually disabled.

Thank you for your time and consideration.



The Members of the Board of Directors and Legislative Committee of VOR
Joanne St. Amand, President
Hugo Dwyer, Executive Director