

Over the past thirty-five years, many VOR families have moved their loved ones into the community - some by choice, others having been pressured or forced out of their ICF homes due to the facilities being closed by class actions or changes in state policies. Many of our members are concerned that their loved ones may be forced into Home and Community Based Services (HCBS) settings in the next few years, as a wave of anti-ICF biases continues to dominate the nation's policy toward services. Justifiably, VOR families have valid concerns about the availability and the quality of services in these settings. ICF/IID is the most comprehensive benefit offered by Centers for Medicare and Medicaid Services (CMS) ICF/IID must meet eight conditions of participation with over 375 specific standards.<sup>1</sup> ICF's must provide Active Treatment,<sup>2</sup> which is not required in HCBS. They are required to report injuries or suspicious incidents directly to state officials. In HCBS group homes, incidents are investigated by the provider and may or may not be reported to state agencies.

We often hear, "Your loved one can receive the same services in the community". This is misleading, at best. We understand that there are good services, but they are not the same, not federally mandated as in an ICF. The Department of Health and Human Service's Office of the Inspector General (OIG), Administration for Community Living, and Office of Civil Rights released a Joint Report in January admitting that under-reporting of incidents of injury, abuse, and neglect was systemic in HCBS group homes across the country. This was based on OIG reports of group homes in three states and confirms reporting from the Chicago Tribune in 2016<sup>3</sup> and the NY Times in 2012<sup>4</sup>. Information about the Joint Report appears on the following page.

One concern is the crisis in staffing within the group home system. Direct Support Professionals (DSP's) have been grossly underpaid. Their wages often fall below those of fast food workers. Many DSP's work extra shifts or second, even third, jobs just to make ends meet and provide for their own families. Turnover is high, 45% nationally, and caregivers are often undertrained and insufficiently supervised. Many group homes have failed to meet required staffing levels. Some have had to close homes as a result of inability to find, train or pay qualified staff.

VOR members who have moved to the community have also raised the issue of difficulty in accessing appropriate dental care. While many larger congregate care facilities offer on-site dental services, this is impossible in a four-bed group home. Providers must find dentists who can treat their residents. Many providers do meet these needs, but in some areas, there are too few dentists or dental clinics that will treat people with I/DD or behavioral challenges. This issue has remained under-addressed by the agencies charged with protecting and advocating for individuals with I/DD, and by the organizations that claim to champion the value of care in community settings. We have been trying to bring more attention to the problem, in hopes that those with the authority and resources, like the ACL or CMS, may use their offices to remedy the situation.

The underlying problem, of course, is a lack of funding. The community of individuals and families are all struggling for a sufficient piece of a small pie, and working against each other instead of helping one another. More money needs to go directly to providing services, overseeing problems, reporting incidents, and improving care. Less money should go to agencies and organizations that waste taxpayer dollars to promote their own agenda. We need to support choice, and we cannot have choice in a vacuum. We must provide a full range of quality services that meet **the needs of all people with I/DD**.

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<sup>1</sup> CMS State Operations Manual: ICF Certification <https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107c02.pdf> P 89-90

<sup>2</sup> According to CMS, Active Treatment means the aggressive, consistent implementation of a program of specialized and generic training, treatment, health, and related services directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible. It includes the prevention or deceleration of regression or loss of current optimal functional status.

<sup>3</sup> Suffering in Secret: Illinois Hides Abuse & Neglect of Adults with Disabilities: <http://www.chicagotribune.com/news/watchdog/grouphomes/ct-group-home-investigations-cila-met-20161117-htmlstory.html>

<sup>4</sup> Abused and Used, <http://archive.nytimes.com/www.nytimes.com/interactive/nyregion/abused-and-used-series-page.html>