

VOR Quality of Care in the Community

June 27, 2021

Jill Barker, Chair

Dental Care in the Community: As you will hear from VOR member Mary Kay Cowen, she has been on a Louisiana dental care task force for more than two years. The Quality of Care Committee has followed along as she has taken on the problem of a lack of Medicaid coverage for dental care for her own brother with severe I/DD to taking on dental care coverage for all adults with severe I/DD who receive funding from Medicaid Waivers. The Task Force issued a detailed Report to the Louisiana Department of Health and Other Relevant Agencies laying out the problems caused by the lack of dental care for this population and recommendations to the State.

Among the needs identified for people with severe and profound IDD are incentives for dentists to include people with severe IDD in their practices, special training in both the medical and behavioral problems for people with severe and profound IDD, and accommodations for people who cannot be treated except with some form of sedation.

A bill to provide Medicaid funding for adults with I/DD on Medicaid waivers was heard before the Louisiana State House in April 2021 and passed the next day.

In addition, the Louisiana Task Force produced an Infographic that provides quick but effective look at the problems associated with providing dental care to people with severe IDD, the problems that develop when they are NOT provided with the care they need, Medicaid funding of dental care vs. NOT funding it and having people with IDD end up with serious medical conditions that Medicaid then funds as medical care.

Mortality studies and attention to the deaths of people who move out of ICFs into community settings and others with the most severe disabilities living in community settings: Committee member Bob Anthony from Virginia has worked with the state of Virginia and the U.S. Department of Justice on assuring follow-up to the 2010 settlement agreement that resulted in the closure of several Virginia training centers (ICFS/IID). Although the process has been frustrating, he has been able to exert some influence in getting the state to properly collect and analyze data on deaths. The State, however, does not do much in-depth investigation and no exploration of systemic causes. They tend to avoid exposing themselves to criticism and are more concerned with following the strict outlines of the settlement agreement, reporting the numbers, but not doing a deeper analysis that would lead to real improvement of the system of care.

COVID-19 and COVID vaccinations: The committee has been following COVID responses in the states represented by committee members. There has been a great deal of variability among ICFs, group homes, and other settings in the seriousness of the disease. Some ICFs and group homes were hit hard, but others sailed through without dire consequences. There was also a surprising number of people with serious and complex medical conditions who contracted the virus with no or few outward symptoms. Once ICF personnel knew more about COVID and how to prevent its spread, many ICFs were very effective in handling the disease. In all the states represented on the committee, there are serious concerns about direct service professionals who have refused to be vaccinated or have been hesitant to get the vaccine.

Disinformation from other advocacy groups: All members of the committee have read or heard disinformation coming from well-funded national disability organizations like the ARC. For example, a few days ago Nicole Norwic, a senior policy staff person at the ARC USA, gave a presentation for the ARC Michigan annual disability policy seminar. Among other misstatements, she said that institutions are always more expensive than community settings and community settings always afford a better quality of life than institutions [ICFs/IID are considered to be institutions under Medicaid law]. She

also stated that institutions are mandatory under Medicaid while Home and Community-Based Services are not. [While nursing homes are mandatory, meaning that a state accepting Medicaid has to provide them, ICFs/IID are not mandatory, but “optional”, in the same way that HCBS is not a mandatory service.] She also implied that institutional care is automatic and immediately available while there are long waiting lists for HCBS resulting in “institutional bias”.

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