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VOR's Response to the Commission on Long Term Care Recommendations

VOR supports the Commission on Long Term Care's recommendations, released September 12, 2013, that called on Congress to recognize the need for a long term services and supports (LTSS) system that is truly person-centered by focusing on *individual* needs to ensure that "people can access quality services in settings they choose," and "improve focus on quality across settings of LTSS - with particular attention to home and community-based services."

"For three decades, VOR has advocated for the right of individuals to receive quality long term care services according to choice and need," said Ann Knighton, VOR's President. "We called on the Commission to do the same. In large measure, the Commission listened, and for that we are grateful."

VOR submitted written comments, calling on the Commission to recognize the need for an array of long-term care options to meet the diverse needs and choices of people with disabilities. VOR also sought Commission support for national background checks, livable wages, licensing, certification, and ongoing training for direct care workers.

In response, the Commission supported a "LTSS system that is able to support family caregivers and attract and retain a competent, adequately-sized workforce capable of providing high quality, person- and family-centered services and supports to individuals across all LTSS settings." The Commission also recommended that the "federal government work with states to enable national criminal background checks for all members of the LTSS workforce."

"In June, VOR called on Congress to support national background checks and to further study the relationship between key direct staffing issues and quality of care," said David Hart, Chairman of VOR's Legislative Committee. "Likewise, the Commission's recommendations support greater attention to background checks, livable wages, adequate training, and retention. In this regard, we're quite pleased."

The Commission's recommendations also support family caregivers, with apparent recognition that far more must be done to ensure an adequate pool of competent direct care workers to alleviate family caregiver burden. VOR is concerned that many families are providing care to their loved ones long beyond what is reasonable and safe, not by choice, but due to lack of alternatives.

"Disability policy has pushed many families into unwilling caretaking roles, leading to emotional, physical and financial stress for some," said Jill Barker, VOR's First Vice President and Chair of the VOR Issues Oversight Committee that helped prepare VOR's comments to the Commission.

“Families who choose to be caregivers should be given all necessary supports, as the Commission recognized,” Barker added. “Likewise, families should also have the option of safe and appropriate out-of-home care. The Commission seems to embrace the need for both options.”

VOR recognizes that the Commission on Long Term Care’s recommendations are only the beginning of this difficult discussion. Its 100-day assignment was not nearly long enough to tackle the financial aspects of delivering long-term care equitably to all people with disabilities, according to need. In recently released “Key Principles,” VOR supports government funding for a full array of long term residential and service options to accommodate the diverse needs and preferences of the disabled population. “Financing for long-term services and supports must be responsive to the needs of *all individuals* with disabilities, recognizing that the cost to care for individuals must necessarily vary and be responsive to varying needs,” VOR’s principles state.

VOR looks forward to participating in ongoing discussions. If Congress accepts the Commission’s recommendation to create a national advisory committee, VOR will seek to be included and involved. As a national organization that has represented individuals with I/DD and their families for 30 years, we have much collective insight, expertise and knowledge to contribute.

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VOR is a national, nonprofit organization advocating for high quality care and human rights for all people with intellectual and developmental disabilities. For 30 years, VOR has been representing families of individuals with I/DD, many of whom experience severe and profound developmental disabilities, have multiple physical disabilities, and are medically fragile or experience dangerous behaviors. For more information, visit www.vor.net.