Speaking out for people with intellectual & developmental disabilities

VOR Positions on Key Federal Legislation Impacting People with Intellectual and Developmental Disabilities

Bill / Program	Description	VOR's Position	Comment
S. 313 / H.R. 657, Achieving a Better Life Experience (ABLE) Act	This legislation would amend the IRS tax code to allow for special savings accounts for children and adults with disabilities, allowing savings for disability related expenses up to $100,000 without risking eligibility for government benefits, such as Medicaid.	**SUPPORT**	VOR supports the ABLE Act, recognizing the opportunities that these saving accounts could provide for individuals with disabilities and their families, without risking life-sustaining Medicaid and public benefit supports. We understand that ABLE Account are not meant to replace the advantages of Special Needs Trusts and will do our part in encouraging families to recognize the differences. VOR will seek strong protections against the possible temptation of financial malfeasance during the forthcoming rulemaking process, if this legislation passes.
H.R. 831, Fair Wages for Workers with Disabilities Act of 2013	Introduced by Rep. Gregg Harper (R-MS), H.R. 831 would phase out and within 3 years repeal Section 14(c) of the Fair Labor Standards Act which allows for special wage certificates to individuals with disabilities who work for less than minimum wage in sheltered or supported employment settings.	**OPPOSE**	VOR supports a full array of employment options, including sheltered workshops, supported employment, and competitive employment based on individual abilities. People with intellectual or development disabilities (I/DD), have a right to choose where they work and where they live. H.R. 831, if passed, would eliminate employment options that are now serving people with severe disabilities very well, leading to isolation, loneliness, and regression for some individuals.

			“These individuals would be denied the option to work in skill development centers and disability-focused non-profit businesses at a wage that reflects their productivity. Eliminating, repealing or restricting Section 14(c) will also eliminate hundreds of thousands of jobs, taking away income and opportunity for people with disabilities. This would especially impact individuals with the most complex physical and cognitive disabilities, replacing skill-based wages with no wages at all.” (ACCSES, 2013).
Developmental Disabilities Assistance and Bill of Rights Act of 2000	It has been 14 years since Congress reauthorized the Developmental Disabilities Assistance Act (DD Act). Authorizations for DD Act appropriations expired in 2007, although Congress has continued to fund these programs. The DD Act programs’ administering agency is the Administration on Intellectual and Developmental Disabilities (AIDD). DD Act programs, including Protection & Advocacy (P&A), DD Councils, and University Programs, operate in every state.	**REFORM and REAUTHORIZE the DD Act:** **A.** Suspend all DD Act program deinstitutionalization activities aimed at evicting fragile Americans from licensed, congregate facility settings ("deinstitutionalization") until such time as Congress has had opportunity to (1) investigate the widespread abuse, neglect and death in small settings serving people with	Oversight of federal AIDD and DD Act programs is inadequate. Through lobbying, class action lawsuits and other tactics, some DD Act programs are using their public funds to achieve dangerous deinstitutionalization policies, evicting vulnerable people with intellectual disabilities from public and private Medicaid-certified homes, disregarding individual choice and the legal right to appropriate services, as required by the DD Act, the Americans with Disabilities Act (as interpreted by the Supreme Court’s Olmstead decision) and Medicaid law. Congress in the DD Act endorsed individual choice and opposed closure of residential institutions: “Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where

		I/DD and (2) make recommendations for changes in policy to prevent further such deaths. **B.** Schedule public hearings on the DD Act as soon as possible, to (1) provide opportunity for affected individuals and their families to testify and (2) determine the extent to which DD Act programs' actions to close and remove residents of Medicaid-certified facility homes are violations of federal law. **C.** Amend the DD Act to enforce DD Act program compliance with the residents' rights to receive appropriate services according to choice and need, as required by law, and to prohibit federally-funded DD Act programs from	the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families." DD Act, 42 U.S.C. 15001(c)(3)(2000). [T]he goals expressed in this Act to promote the greatest possible integration and independence for some individuals with developmental disabilities may not be read as a Federal policy supporting the closure of residential institutions. [(H. Rep. 103-442 (March 21, 1994)].

		pursuing the closure of any Medicaid-certified home serving people with profound intellectual and other developmental disabilities (e.g., ICFs/ID), in violation of the residents' civil rights. **D.** Limit the reauthorization cycle to three years to assure ongoing Congressional oversight.	
Labor, HHS, Education and Related Agencies Appropriations for U.S. Department of Health and Human Services' (HHS) Agencies Supporting Deinstitutionalization Activities	Several HHS agencies, such as the Administration on Intellectual and Developmental Disabilities (AIDD) and its DD Act programs; National Council on Disability (NCD); and Centers for Medicare & Medicaid Services, support programs and policies in support of	**OPPOSE** funding for HHS funding used to downsize or close Medicaid-licensed facility homes for people with I/DD. **PROPOSE** Labor/HHS Appropriations Language to prohibit the use of federal funds in support of deinstitutionalization. **Proposed language:** "No funds appropriated for any Department of Health	Deinstitutionalization activities, including advocacy, lobbying, class action lawsuits, and other tactics by some HHS-funded agencies which result in the downsizing and closure of HHS-licensed are a cruel and absurd use of federal funding. These closures often lead to human tragedy. Medicaid-licensed facility homes, including Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), are uniquely suited to meet the residents' profound support, health care and behavioral needs. Tragedies are widespread and predictable when fragile citizens are removed from specialized care. The legally-protected rights of families and legal guardians to serve as primary decision-

		and Human Services program may be used to attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities or any other Medicaid-licensed facility serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic resident abuse. Nothing in this provision shall prevent any program from assisting a resident or residents who seeks the program's help to transition from the facility. Such action shall affect only such resident or residents. Nothing in this provision shall be construed to require a State (as defined for the purposes of title XIX of the Social Security Act) to include Intermediate Care Facilities for Individuals with Intellectual Disabilities services as an option under its Medicaid plan under such title."	makers are routinely ignored.
Appropriations for		**OPPOSE** funding for Justice Department funding	In several states, families of individuals with profound I/DD who require specialized facility-based care have directly faced Justice

the U.S. Department of Justice Supporting Deinstitutionalization Activities		used to downsize or close Medicaid-licensed facility homes for people with I/DD. **PROPOSE** Commerce, Justice, Science and Related Agency Appropriations language to prohibit the use of federal funds in support of deinstitutionalization. **Proposed language:** “**(a)** IN GENERAL. Except as provided in paragraph (b), no funds appropriated for the Department of Justice may be used to attempt to downsize or close a Medicaid-licensed Intermediate Care Facility for Individuals with Intellectual Disabilities or any other Medicaid-licensed facility serving people with intellectual disabilities, unless the purpose of the action is to remedy systemic resident abuse. **(b)** EXCEPTIONS. Nothing in this provision shall— (a) prevent any program from assisting a resident who seeks the program’s help to transition from the	Department usurpation of their fundamental decision-making authority with regard to the services and supports their family members receive. These Justice Department actions were taken with a view that families simply require education about community based options. This dictatorial, paternalistic attitude is pervasive throughout the Justice Department’s national activities with regard to enforcement actions. Congressional reform, to require DOJ to fulfill the ADA’s choice requirement is required and could be achieved by conditioning appropriations accordingly.

		facility, to the extent that it affects only such resident; or (b) be construed to require a State (as defined for the purposes of title XIX of the Social Security Act) to include Intermediate Care Facilities for Individuals with Intellectual Disabilities services as an option under its Medicaid plan under such title.”	
H.R. 3717, Helping Families in Mental Health Crisis Act of 2013	The Helping Families in Mental Health Crisis Act of 2013 tackles various aspects of the mental health system in America, including the establishment of an HHS assistant secretary for mental health and substance abuse to coordinate mental health and substance abuse work across various executive offices. The bill also proposes changes to privacy regulations to allow caregivers of individuals with serious mental illness access to health and education information under certain circumstances; and major	**SUPPORT** provision that calls for PAMI reform because such reform advances VOR’s opposition to federal agencies using federal funds to eliminate services and supports based solely on ideology and not individual support needs and choice. **NEUTRAL** as to other provisions, as bill applies to people with mental illness, not intellectual and developmental disabilities.	

	changes to the Substance Abuse and Mental Health Services Administration (SAMHSA); among other proposals. Importantly, the bill includes proposed reform to the Protection & Advocacy System for People with Mental Illness (PAMI), to prohibit PAMI from using federal funds to lobby or file class action or systemic reform lawsuits, but allowing form individual cases of abuse or neglect.		
Medicaid	Protect and preserve Medicaid funding that the most vulnerable, including people with I/DD, rely on for life-sustaining long term care and services. According the American Health Care Association, "The majority of Americans who require long term care and services – virtually all persons with developmental disabilities	**PROTECT and PRESERVE**	Most Medicaid services for people with intellectual and developmental disabilities are considered "optional" - provided at the option of each State - including some life-sustaining long term care benefits such as home and community based services (HCBS), personal attendant care, case management, and Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID). Other basic health care services are optional Medicaid benefits, such as prescribed drugs, clinic services, dental care, physical therapy, prosthetic devices, and specified medical and remedial care.

	(DD), nearly 64 percent on nursing home patients and about 19 percent of assisted living residents – rely on Medicaid to pay for their care each day. The largest payor of long term care and services, Medicaid represents a blend of both federal and state dollars paid at a rate set by each state – rates that often fail to cover the actual cost of providing this type of care.		Most people residing in ICF/IID homes or in other congregate care settings (including those funded by Medicaid HCBS prorams), have profound intellectual disabilities and complex medical and care needs. These "lifeline" services are not "optional" in the lives of those who need them. Strong Congressional leadership is necessary to ensure that our nation's admirable history of supporting our most vulnerable citizenry will not be lost to the chopping block. Most persons with I/DD and others with disabilities rely on Medicaid for basic health care and support needs/
H.R. 2123, Special Needs Trust Fairness Act	Under current law, individuals with disabilities can't establish their own special needs trusts without petitioning a court; instead, a parent, grandparent, guardian, or court creates the trust for the disabled individual. While this process is practical for those individuals with limited mental capacity, it is unfair to those who are	**SUPPORT**	VOR supports this well-meaning legislation recognizing that H.R. 2123 does not affect the powers of court-appointed guardians, nor would it allow a "person who has been judicially found in need of a guardian" to unilaterally create a special needs trust or any other trust. VOR cautions that regardless of the rights conferred upon capable individuals with disabilities by H.R. 2123, that the assistance of legal counsel is still necessary.

	physically disabled, yet mentally capable.		
H.R. 1601, Supplemental Security Income (SSI) Restoration Act	The bill would update the SSI resource limits to $10,000 for an individual or $15,000 for a couple; and would also update the general income disregard to $110 per month and the earned income disregard to $357 per month. All increases would take effect in 2015 and be adjusted for inflation each year thereafter. The bill would also repeal the in-kind support and maintenance provision and repeal the SSI transfer penalty.	**SUPPORT**	SSI resource limits have not been adjusted since 1989. The proposed limits of $10,000 per individual and $15,000 per couple represent the 1989 limits adjusted for inflation. Likewise, the general income disregard has not been adjusted for inflation since 1972. VOR would also support Executive Action to increase SSI resource limits and SSI general income disregard.
H.R. 975, the Court-Appointed Guardian Accountability and Senior Protection Act	Proposes federal grants to the highest courts of states to conduct demonstration programs that assess adult guardianship and conservatorship proceedings for seniors, including the appointment and the monitoring of the performance of court-appointed guardians and conservators; and (2) implement necessary	**NEUTRAL, as bill applies to guardianship of seniors, not people with disabilities.**	VOR will closely monitor this legislation to ensure it is not expanded to include people with disabilities.

	changes based on assessments, such as requiring background checks for all potential guardians and conservators, and establishing systems that enable electronic filing and review of the annual accountings and other required conservatorship and guardianship filings.		