

VOR's 2023 Legislative Requests:

Promote Safety for Recipients of Medicaid Long-Term Supports & Services

VOR is a national non-profit organization advocating for high quality care and human rights for *all* people with intellectual and developmental disabilities (I/DD) and autism. We support a full range of residential and employment opportunities for this diverse cohort of individuals and the rights of individuals, families, and guardians to choose the most appropriate services from among those options.

In this, our 40th anniversary year, we are focused on the safety of people with I/DD. Our greatest concern is the critical shortage of Direct Support Professionals (DSPs), Certified Nursing Assistants (CNAs), and other essential caregivers who provide support for vulnerable populations through Medicaid Long-term Services and Support (LTSS). We recognize that addressing this problem will require additional federal funds, and we are not naïve to current federal fiscal constraints. However, this is a crisis and must be a congressional priority.

There are a few requests that we believe can be achieved with bipartisan support. We are reaching out to Members of Congress in hopes of finding champions who will introduce bills that will make substantive, positive changes to the LTSS systems in order to better protect vulnerable individuals. Several states have adopted measures that achieve these goals, and we believe their success warrants adopting federal legislation.

1. **Improve systems for reporting incidents of abuse and neglect.** Currently, incidents and suspected incidents of abuse and neglect are required to be reported to the provider of residential services. Unfortunately, multiple reports from the Inspector General of the Department of Health and Human Services during the last decade have found that up to 99% of those incidents, including hospitalizations, are never reported to the appropriate state agencies. We would like for Congress to request a federal review to subsequently use to establish federal best practices for reporting and investigating incidents of abuse and neglect, and to set guidelines for penalties for such acts and for the failure to report such acts by individuals or agencies responsible for the care and well-being of vulnerable individuals.
2. **Promote the use of cameras in LTSS facilities.** To better protect our loved ones from abuse and neglect, we believe that cameras in common areas, entranceways, and vans or buses used to transport individuals with I/DD can greatly decrease incidents and clarify the nature of incidents where a caregiver might be unjustly charged with abusing a resident.
3. **Require Protection and Advocacy agencies to perform unannounced inspections** of all facilities providing LTSS services at least once per year. Currently, most facilities receive pre-arranged inspections, and in some states, they are inspected at intervals exceeding three years. Violations of state requirements should require follow-up inspections within six months.

VOR appreciates your work on behalf of people with I/DD and autism, and we look forward to future discussions with you on these critical issues. Please reach out to Hugo Dwyer, VOR's Executive Director at hdwyer@vor.net, with any questions and to find a time to meet on these policy options.

Preventing Abuse and Neglect: Improving Procedures for Reporting and Investigating Incidents

In 2016, the Inspector General of the Department of Health and Human Service (HHS) issued a report finding that the State of Connecticut failed to comply with federal and state requirements for critical incidents involving developmentally disabled Medicaid beneficiaries.¹ A series of related investigations followed, in states including Maine, Massachusetts, Wisconsin, and Pennsylvania, showing similar results. In 2018, a joint statement was issued by three agencies within HHS, the Administration for Community Living, the Office of the Inspector General, and the Office of Civil Rights, admitting to the failures in reporting and investigating such incidents, and indicating that there would soon be changes within the system to remedy this lack of oversight.² Yet, any reforms enacted have proven ineffective in addressing these horrific events.

According to a 2022 report from the Protection and Advocacy for Individuals with Mental Illness (PAIMI) grantees to HHS, most states have no mandatory reporting statutes, central registries, or other statewide systems to capture incidents of restraint, seclusion, serious injuries, or fatalities. Instead, caregivers are expected to report incidents of abuse and neglect, and suspected incidents, to the provider agency that owns and operates the facility in which such incidents have occurred. **The providers themselves determine whether or not to report the incident to state authorities.** Many cases, including some that result in hospitalization, are never reported. It is not uncommon for an abusive employee to be dismissed, with no record of their possible transgressions, resulting in the abuser to be hired by another provider who is not aware of their history. This must change.

We believe that Direct Support Professionals, nurses, and others charged with the care of vulnerable individuals should be required to report incidents directly to state authorities as well as to the providers who employ them, and that providers be required to notify parents, guardians, or a designated contact within 24 hours of the incident. Providers must also file a report to state agencies detailing their initial findings within a reasonable period of time (72 hours, perhaps). State agencies should have investigative units available and the authority to press charges if necessary. We believe there should also be penalties for failing to report incidents of abuse and neglect, even if the observer did not take part in the act.

Varying levels of systems are in place in several states. Louisiana has a comprehensive system of requirements and protocols³, and New Mexico and other states have been trying to improve their systems for reporting and investigating such incidents⁴. Another legislative model is [H.B. 3545](#), introduced by Illinois State Representative Charles Meier.⁵ This bill would require reporting of incidents within five days and impose stiff penalties for failing to report such violations.

VOR looks forward to working with you to enact federal laws to ensure patient and employee safety throughout the disability community.

¹ Connecticut Did Not Comply with Federal and State Requirements for Critical Incidents Involving Developmentally Disabled Medicaid Beneficiaries, A-01-14-00002 - 11400002.pdf - <https://oig.hhs.gov/oas/reports/region1/11400002.pdf>

² Joint Report, Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight <https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf>

³ Louisiana Revised Statute on Abuse and Neglect - <http://legis.la.gov/Legis/Law.aspx?d=78522>

⁴ <https://www.governor.state.nm.us/2023/03/20/state-to-developmental-disabilities-program-providers-if-you-abuse-or-neglect-those-in-your-care-we-are-coming-for-you/>

⁵ Illinois General Assembly 2023-24

<https://ilga.gov/legislation/fulltext.asp?DocName=&SessionId=112&GA=103&DocTypeId=HB&DocNum=3545&GAID=17&LegID=148715&SpecSess=&Session=>

Preventing Abuse and Neglect: Placing Cameras in Common Areas

Installing cameras in critical locations has become an accepted means of preventing crime, increasing transparency and accountability, and protecting vulnerable individuals. We use cameras in schools to protect our children and around houses of worship to protect our religious freedom. We rely on cameras to protect people in residential settings, from single-family homes and apartment buildings to public housing complexes to gated communities. Cameras have become essential to any business where money is exchanged, from banks to bodegas to all-night gas stations. The use of cameras to protect assets, employees, and innocent bystanders has been embraced by both the public and private sectors. Cameras are nearly everywhere.

Few, however, are in facilities that house our most vulnerable individuals, those with intellectual disabilities and autism (ID/A) and the aging community.

VOR is working to change this. Cameras can prevent abuse and neglect, and they provide evidence of the details of what has transpired when such incidents have occurred. Providers and managers may view recordings to verify an employee's abusive actions, or to vindicate a caregiver's response to a situation where a resident might have lashed out in a manner that causes self-injury or harm to others.

Cameras can provide clarity and transparency – protecting the employer, employee, and resident.

Currently, many states allow families or guardians to install cameras in the resident's bedroom, with various limitations. VOR supports this voluntary option being available at the federal level.

Because we understand privacy concerns, we agree that there are some areas that should remain camera-free, regardless of the risk. But there are many places where cameras would be effective in preventing abuse and in clarifying the details of incidents that have resulted in injuries. These areas include common rooms, dining areas, and entrances and exits to the buildings. Cameras should also be installed in vans or buses that transport ID/A and elderly individuals.

We would like to see federal support for the use of cameras in these common areas to better protect people with I/DD and autism, and we are asking for your support in proposing a grant program to provide for the cost of purchasing and installing such technology for qualified facilities and provider agencies.

Illinois and New Jersey each have bills that align with our federal legislative goals:

- New Jersey: "Billy Cray's Law"
[A. 2483](#) & [S. 1897](#) (the bills are similar but not identical)
- Illinois: "Assisted Living Monitoring"
[HB 2998](#)

We urge Congress to pass legislation that protects our most vulnerable population and those who are working to care for them. VOR looks forward to working with you on this timely and necessary legislative initiative.

Preventing Abuse and Neglect: Require Protection and Advocacy Agencies to Perform Unannounced Inspections of ALL Medicaid-Funded Long-Term Services & Supports (LTSS) Facilities

Every state's Protection and Advocacy Agency (P&A) is charged with protecting vulnerable individuals receiving long-term services and supports through Medicaid. P&As are funded by the Administration for Community Living (ACL). According to the ACL's website,¹ P&As have the legal authority to:

- Investigate suspected abuse or neglect and seek justice for victims and their families.
- Have access to records and facilities necessary to investigate abuse or neglect or to monitor the treatment and safety of residents.
- Pursue litigation and all other appropriate remedies under federal, state, and local law.
- Provide information and referrals regarding entitlements to services and other legal rights.
- Educate policymakers on needed reforms to disability-related laws and services.

P&As are allowed discretion in how they use their resources, and over the past decades there has been a decline in the inspections and oversight necessary for patient care and safety. In some states, other agencies have stepped in to turn the tide on the horrific events that have gone unnoticed and unreported.

Recently, in response to a serious incident of abuse in a group home, New Mexico's Department of Health initiated an extensive examination of its own system. The state began a forensic review of its entire Developmental Disabilities waiver system, conducting in-person wellness checks on the 6,815 individuals with intellectual and developmental disabilities in the care of private providers. In the homes they visited, the investigators found 26 sites in need of repairs, and in 42 sites they reported allegations of potential abuse, neglect or exploitation. New Mexico has terminated contracts with four of the private providers.² There has been no mention of any of this on the website of the state's P&A, Disability Rights New Mexico.

In Ohio, the state legislature holds hearings every two years to examine the effectiveness of its P&A: Disability Rights Ohio.³ Last November, families appeared before legislators to testify about their experiences with the agency, and the families' complaints about their P&A are worth [viewing](#). On April 11, a joint commission of legislators submitted a formal [report](#) and recommended to the Governor that the state "redesignate the current P&A agency for intentionally not protecting and advocating for all individuals with disabilities."

Illinois State Representative Charles Meier has introduced [legislation](#) that is an excellent model for how Congress can improve residents' care and safety in ALL settings.

VOR is asking Congress to enact legislation requiring unannounced inspections of ALL Medicaid-Funded Long-Term Services & Supports Facilities, at least once each year, with repeat inspections for violations as necessary. Further, inspection reports should be submitted to the state Developmental Disability agencies. We look forward to working with you to improve care for ALL individuals in the disability community.

¹ <https://acl.gov/programs/pa-programs>

² New Mexico Department of Health - <https://www.nmhealth.org/news/information/2023/4/?view=1949>

³ *Ohio Section 5123.603 | Joint committee to examine protection and advocacy system* requires the state legislature to hold hearings to review the effectiveness of its P&A and determine if it is meeting the needs of the I/DD community
<https://codes.ohio.gov/ohio-revised-code/section-5123.603>

Addressing the Workforce Crisis

The American system of Developmental Disability Services (DD) relies on an extensive workforce of caregivers. In addition to the highly trained doctors, dentists, psychiatrists, nurses, and behavioral and physical therapists who work with people with intellectual disabilities and autism (ID/A) and the aging populations, there is a vast workforce of Direct Support Professionals (DSPs) and Certified Nursing Assistants (CNAs) who perform the daily tasks of caring for, and caring about, our most vulnerable citizens. **They are truly the backbone of the DD system.**

Currently, there is a critical shortage of DSPs. The national turnover rate, with people leaving the job in less than one year, stood at around 45% nationally from 2016 -2020, and was as high as 80% in some states.^{1, 2} These numbers are likely to increase after the end of the Public Health Emergency. Across the country, providers of Long-Term Supports and Services (LTSS) including nursing homes for the aging population, group homes and in-home services, intermediate care facilities (ICFs), day programs for people with intellectual disabilities and autism (ID/A), and nursing homes for the aging population have all been forced to cut back services, even closing facilities due to this shortage. According to a 2023 report from ANCOR, 83% of providers are turning away new referrals, 63% are discontinuing programs and services, and 55% are considering closing additional services. 92% of providers are struggling to achieve quality standards.³

There are several reasons for the shortage - long hours, the fact that double and triple shifts are mandatory if and when no replacement shows up for the next shift, the lack of any defined career path or opportunity for advancement, poor training and lack of certification standards, and the ever-present risk of personal injury when a client has an aggressive or violent behavioral episode. Those factors all contribute to the high turnover rates. The biggest deterrent to hiring new workers is the low pay.

DSPs are paid through the Centers for Medicare and Medicaid Services (CMS), and their pay is tied to the federal minimum wage of \$7.25 per hour. \$7.25. That's the about the average cost of a cheeseburger in the U.S. It is not a living wage, and certainly not enough to support a family. Even when state legislatures vote every two years to bring the wage up to their state minimum wage, or higher, to try to remain competitive, they still fall short of what fast food chains or big box stores offer. These workers deserve more. They help with personal hygiene, toileting and diapering adults, brushing their teeth, shaving, feeding special diets and pureeing food, inserting J-tubes and G-tubes, monitoring for Pica and self-injurious behaviors, handling seizures and violent outbursts. They offer love, devotion, and understanding to people who don't easily communicate. These individuals deserve pay and certification that reflects their work.

Despite the fact that there are more than 4.5 million people working as DSPs in this country, there is still no recognition of this workforce in either the Department of Labor's Bureau of Labor Statistics or in the Office of Management and Budget.

We need Congressional action to fix this. Current bills, like the Better Care Better Jobs Act and the HCBS Access Act have provisions that would increase salaries and provide training for DSPs who work in HCBS-funded settings *only*. This leaves out a considerable number of DSPs - those who work in ICFs, non-HCBS nursing facilities, non-HCBS day programs, and more. Since all of these service providers draw from the same pool of workers, non-HCBS providers will be unable to compete for workers against the higher wages offered by HCBS providers. Ultimately, the people who rely on those providers, our most severely disabled and our elderly populations, will suffer. There will be no one to attend to their needs. We cannot allow this to happen.

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Addressing the Workforce Crisis - How Congress Can Help:

1. Increase wages and pay scales equitably for ALL Direct Support Professionals who work with people receiving services through Medicaid.

DSP employees should be treated equally regardless of the type of facility in which they serve, not based on the funding stream, or silo, within the CMS system. Current legislation should be amended to reflect this.

Further, since wages for DSPs are currently tied to the federal minimum wage, there are several approaches for updating this policy. VOR supports dialogue that works to develop the policy and legislation that supports employees, employers, patients, and the states.

2. Support a career path and certification programs for Direct Support Professionals.

Being a caregiver is more than a job. It is a profession. A profession within the American Health Care System. Let's treat it as such. As with any other professional service, there should be rewards for experience and length of service. There should be certifications for training in different methodologies and for gaining better understanding of how different intellectual disabilities manifest and change through the course of a person's life. There should be a career path for advancement as a DSP, or into other related health care professions, such as credit towards a nursing degree or an administrative position.

3. Create a Standard Occupational Classification for Direct Support Professionals.

We ask that members of Congress support legislation that will direct the Bureau of Labor Statistics and the Office of Management and Budget to establish a standard occupational classification (SOC) for Direct Support Professionals. SOC's enable the DOL to collect data and influence policymaking to establish standards and improve the ability of providers in recruitment, training, retention, and advancement of a quality workforce. We hope that legislators will sign on to cosponsor the bi-partisan **Recognizing the Role of Direct Support Professionals Act (S. 1332 / H.R. 2941)**

4. Require best practices for high standards in hiring of Direct Support Professionals.

Background checks are required in all states, but the standards vary greatly. More thorough-background checks reduce the potential for instances of abuse and neglect of clients. They also help reinforce the safety of other caregivers, and make them feel assured that their coworkers have everyone's best interests at heart.

We would suggest that all states use the FBI's IAFIS database, and that there be a uniform code for hiring DSPs, so that all people in all states have equal protection against abuse and neglect. One example of a well-designed system is currently in use in Ohio.⁴

We cannot emphasize enough how drastic this workforce crisis has become. Imagine the far-reaching effects on the nation's economy if this sector of the labor market disappears. Please act now.

¹ President's Committee for People with Intellectual Disabilities, Report to the President 2017, Full Report, p. 5
https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

² National Core Indicators, National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI) - 2020 Staff Stability Report, p. 30
https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiP-bWO2af-AhUtF1kFHQQIBOIQFnoECBYQAQ&url=https%3A%2F%2Flegacy.nationalcoreindicators.org%2Fupload%2Fcore-indicators%2F2020StaffStabilitySurveyReport_FINAL.pdf&usg=AOvVaw0tYbPr2wZJ5z3QoNAjwEgg

³ The State of America's Direct Support Workforce Crisis 2022. Alexandria, VA: ANCOR, 2022.
<https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2022/>

⁴ Ohio Administrative Code (OAC): 5123:2-2-02: Background investigations for employment.
<https://codes.ohio.gov/ohio-administrative-code/rule-5123-2-02>

Available for download at: <https://dodd.ohio.gov/forms-and-rules/rules-in-effect/5123-2-02>