

Talking Points: Supporting the Direct Care Workforce Campaign

About The Arc New York

The Arc New York is a family-led organization that advocates and provides supports and services to people with intellectual, developmental, and other disabilities, emphasizing person-centered choice and community engagement. With 37 operating Chapters across New York state, our organization is the largest voluntary provider in New York state, supporting more than 60,000 individuals and families and employing more than 30,000 people.

Overview of Goals for Legislative Meetings and Rallies

We would like legislators to hear your perspective on the importance and impact of Direct Support Professionals (DSPs) in your life and in the lives of your loved ones. If you are a DSP, let legislators know why you chose this career and what they can do to support you. If you are an individual, family member, self-advocate or anyone else invested in the future of supports and services for New Yorkers with intellectual and developmental disabilities (I/DD), share how important DSPs are to you. Using your own words, speaking from the heart, and sharing your experience is always best.

Please feel free to use the talking points below to assist with telling your story. If you would like include additional information, you can refer to the [Better Care Better Jobs Act](#) overview and financial impact sheets specific to Chapters.

Educate Your Representative About HCBS

Home and community based services (HCBS) provide opportunities for New Yorkers with I/DD to receive services in their own home or community rather than institutions or other isolated settings. These services include day habilitation services, residential, respite care, service coordination, and adaptive technologies. Costs are shared between states and the federal government, with NYS receiving close to the minimum federal match of 50%. The NYS Office for People with Developmental Disabilities (OPWDD) administers this HCBS waiver program, which is the primary funding mechanism for supporting individuals in the community. HCBS provide a variety of services and supports uniquely tailored and individualized to meet each person's needs and goals. Over 80% of these services are provided by voluntary non-profits like The Arc New York.”

Talking Points for Families, Self-Advocates, DSPs, and Allies

Direct Support Professionals (DSPs) are essential workers who provide daily care, services and supports to people with intellectual and developmentally disabilities 24 hours a day, 7 days a week.

- These professionals have been underpaid and undervalued for too long, they are asked to do so much for so little and deserve a living wage.
- Caring for people with complex needs is a rewarding yet challenging job, which requires ongoing training, high-level of responsibility, and skill.
- We need to separate the politics from the policy and recognize that investing in home and community based services (HCBS) crosses all party lines.
- Investment in our care economy can be compared to investment in our infrastructure.
 - People rely and depend on the safety and availability of supports and services just as they would roads, bridges, and utilities.
 - In the case of human services, the neglect has spanned several decades without proper maintenance and, at times, completely overlooked.
 - Cracks are showing in a workforce emergency that threatens to leave New Yorkers with I/DD without staff to support basic services, let alone the full community integration they deserve.
- The investment of funds from the Better Care Better Jobs Act would go directly to supports and services. In turn, those dollars are reinvested within local communities for basic needs, entertainment, and services.
- At some point in all our lives either we or someone we love will need to receive supports provided through home and community based services (HCBS).
 - It is not matter of if, but when, so we must ensure that this infrastructure is strong, sustainable, and accessible for all people.

Workforce Data

Here are a few sobering state-wide statistics from the most recent New York Disability Advocates (NYDA) Provider Survey to highlight this dire workforce emergency. The statewide vacancy rate for DSPs escalated by 74% over the past two years

- 25% of DSP positions are currently vacant across the state
- 93% of providers saw a reduction in job applicants in the first quarter of 2021
- 40% of providers were unable to open programs due to staffing shortages during Q1 2021
- 48% of providers were forced to close programs or reduce operations during Q1 2021 because they lacked the staff to sustain them
- Most recently, senior and administrative staff at 69% of providers were pulled from their leadership responsibilities to cover direct support shifts

Additional Supporting Talking Points for EDs/Board Members

We need massive investment to support our workforce with a wage commensurate with their responsibilities and experience.

- The majority of the DSP workforce are women and a large percentage are people of color (approximately 73% women, 42% black/African-American, and 13% Hispanic/Latinx).
- This emergency is only escalating, and will continue to force interruptions in essential services, program closures, and loss of care throughout the state.
- DSP responsibilities far exceed those of entry-level minimum-wage employees and we have to face reality that they are not receiving equal pay for equal work.
- The proposed investments in HCBS and our workforce are a result of years of advocacy, with data to support the need, now is the time to investment in our workforce, our loved ones, and our communities.
- We find ourselves in a dangerous position, facing safety concerns for our overly-extended workforce and the people they support.
- Not only is this unsustainable, but it is also untenable that after years of progress and leading the way that we would allow the system to crumble in New York state.
- Providers are finding it increasingly difficult to recruit and retain a strong workforce. A Standard Occupational Designation (SOC) designated by the Bureau of Labor and Statistics would help to appropriately classify this profession, make DSPs co-equal with peers, affect compensation rates, and create opportunities for advancement.

What are We Asking For?

Support and fully fund the Better Care Better Jobs Act (S.2210) proposed by Senators Casey, Wyden, and Leader Schumer, Representative Dingall, et al.

- Provides permanent 10 percentage point increase in the federal Medicaid match for delivering HCBS, in addition to funding for improvements and innovation would be life-changing for the backbone of our field, the DSP
- This bill operationalizes the proposed \$400 billion care economy infrastructure plan proposed by President Biden
- During budget reconciliation negotiations, please do not allow the elements of the bill, including the full investment, to be stripped to a fraction of what it was.
- Establish a Direct Support Professional Standard Occupational Classification and sponsor: **S.1437 - Recognizing the Role of Direct Support Professionals Act**
 - This bill would direct the Office of Management and Budget to revise the Standard Occupational Classification (SOC) system to establish a separate code for Direct Support Professionals, ensuring better data on these pressing workforce challenges. By improving data collection, this bill will:

- Provide states and the federal government with more accurate information about the workforce trends for Direct Support Professionals to help identify workforce shortage areas and report accurate turnover rates.
 - Help identify where to implement targeted workforce training programs for Direct Support Professionals so that trained workers can meet local workforce needs.
 - Recognize the unique role that Direct Support Professionals play in supporting individuals who experience disabilities and raise awareness of critical workforce needs.
 - Pave the way for professional certifications, education, and experience to be linked to commensurate pay
- Provide grant opportunities for the recruitment, retention, and advancement of direct care workers and sponsor: [H.R.2999 - Direct Creation, Advancement, and Retention of Employment \(CARE\) Opportunity Act](#)
 - The sponsors of this bill assert:
 - Many direct care workers lack access to a career pathway or advanced training opportunities. This limits their ability to build competency and expertise in their field that, when gained, may lead to an increase in their earning capacity.
 - Direct care workers provide most of the paid, hands-on care for older individuals and individuals with disabilities
 - From 2014 to 2024, home care occupations are projected to add more jobs than any other single occupation, with an additional 633,100 new jobs. Home care is also among the top 10 fastest-growing occupations

Overview of Better Care Better Jobs Act (BCBJA) from the Office of Senator Casey

The Better Care Better Jobs Act (BCBJA) includes substantial funding for states to expand access to Medicaid home and community based services (HCBS) and addresses the decades-long workforce crisis and our current emergency. With a proposed **investment of \$400 billion** nationwide, this is a once in a generation opportunity to secure the future of HCBS supports for our loved ones and create a sustainable workforce model to aid in the recruitment and retention of a skilled direct care workforce.

BCBJA would enhance Medicaid funding for home and community based services (HCBS). States would be eligible for a permanent **10 percentage point increase** in the federal Medicaid match for delivering HCBS, as well as enhanced funding for administrative activities associated with improvement efforts. It is imperative that we impress upon our federal representatives the need for this funding and inform our state representatives of their responsibility to use the funds as intended and find ways to circumvent the maintenance of effort (MOE)

- To receive these dollars, **states must:**
 - Strengthen and expand the HCBS workforce by addressing HCBS payment rates to *promote recruitment and retention of direct care workers*
 - Regularly updating HCBS payment rates with public input
 - Passing rate increases through to direct care workers to increase wages
 - Updating and developing training opportunities for this workforce as well as family caregivers.
 - Strengthen and expand access to HCBS
 - Address access barriers and disparities in access or HCBS utilization
 - Expand financial eligibility criteria for HCBS to the federal limit
 - Cover personal care services
 - Facilitate access through the adoption of “no wrong door” enrollment systems, use of presumptive eligibility, and improvement of outreach and education efforts
 - Expand supports for family caregivers, including respite care
 - Develop or improve programs to allow working people with disabilities to access HCBS
 - Expand access to behavioral health services and coordination with employment, housing, and transportation supports.
 - Show improvement over time
 - Demonstrating improved availability of services
 - Reduced disparities in accessing and using HCBS
 - Evidence of competitive wages and benefits for workers
 - Increases in HCBS spending
 - Comply with a strong maintenance of effort for HCBS eligibility and benefit standards to ensure that additional federal dollars go towards growing and improving HCBS programs.
 - Encourage innovative models that benefit direct care workers and care recipients:
 - Provide additional incentives to help states build HCBS workforce programs that register direct care workers
 - Help connect them to seniors and people with disabilities seeking care
 - Facilitate coordination between the state and direct care workers
 - Support care safety and quality; and help workers organize, among other functions
 - Facilitate state planning:
 - Provides funding for states to develop HCBS infrastructure improvement plans with public input, to outline how they would expand access to HCBS, strengthen the workforce, and meet requirements tied to increased federal Medicaid funding
 - States would be required to develop these plans in order to receive enhanced federal Medicaid funding for HCBS.
 - Appropriated funds supports quality and accountability

- Provide funding to the Centers for Medicare & Medicaid Services to carry out the bill's programs
- Conduct oversight and monitoring
- Offer technical assistance to states participating in the funding opportunities described above
- Participating states would be required to establish state HCBS ombudsman programs to support care quality
- Require all state Medicaid programs to adopt HCBS quality measures
- Permanent spousal impoverishment protections
 - Permanently authorize protections against impoverishment for individuals whose spouses are receiving Medicaid HCBS.