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THE WORKFORCE CRISIS

For decades, New York state has not invested enough to sustain essential supports and services for New Yorkers with intellectual and developmental disabilities (I/DD). The nonprofit agencies that provide these supports are funded almost entirely by Medicaid, and more than 70 percent of their costs go directly to wages for staff who provide direct care.

Without adequate funding, I/DD providers are unable to offer competitive wages to recruit and retain the skilled direct support staff that provide the foundation of care for more than 140,000 New Yorkers with I/DD.

The existing workforce crisis escalated dramatically in the wake of the COVID-19 pandemic. Without immediate action, this emergency will continue to force service reductions, program closures, and loss of care people with I/DD throughout the state.

THE NUMBERS

According to a recent survey conducted by New York Disability Advocates, including all Chapters of The Arc New York:

- **93%** of providers saw a decrease in job applicants this year
- Statewide vacancy rates increased **75%** since pre-pandemic levels
- **25%** of all DSP positions are currently vacant statewide
- **48%** of providers were forced to close or reduce programs due to lack of staff
- **39%** of providers did not reopen programs due to staff shortages
- Senior & administrative staff at **69%** of providers were pulled from leadership responsibilities to cover direct care shifts.



THE FOUNDATION OF CARE

DSPs are the backbone of services for New Yorkers with I/DD. Their 24-hour support includes:

- Supporting activities of daily living
- Administering medication
- Tube feeding, wound care, mobility support, and oxygen administration
- Delivering physical and behavioral health services
- Teaching money management
- Transporting to appointments and community activities

DSP staff shortages directly impact people with I/DD and put this vital system of supports in jeopardy.

THE SOLUTIONS

DSPs are highly skilled essential workers and a critical component of New York's public health system. They deserve a living wage. Immediate action is needed from the State to address the current crisis and implement long-term solutions to address the I/DD sector's workforce challenges. This will require a multi-pronged approach to elevate the DSP position and innovate within the field.

ESTABLISH A LIVING WAGE

Include not-for-profit providers in the statutory Cost-of-Living-Adjustment which has been notwithstanding for more than a decade. Unlike for-profit entities that have the ability to raise prices, not-for-profit providers have only been able to pay rates as afforded by the funding provided by OPWDD, which has caused stagnation in the wages.

CREATE A STANDARD OCCUPATIONAL CODE

DSP wage and occupation data is not accurately captured by the Bureau of Labor Statistics, leading to an understatement of the workforce crisis. A discrete standard occupational classification for DSPs will yield the appropriate data to assist states and federal agencies in better understanding the workforce and addressing challenges.

EXPAND THE BOCES PROGRAM

A successful pilot program with Capital Region BOCES teaches students the skills necessary for a long-term career supporting people with disabilities. The pilot project aligns state education standards with quality DSP training metrics and offers certification in six areas. We recommend that the State establish a plan to replicate this program statewide by 2023.



PROFESSIONALIZE THE DSP ROLE

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. By providing grant opportunities for the recruitment, retention, and advancement of direct care workers, we can enrich the DSP role, and provide opportunities for career growth.

Learn more, and find out how you
can join our advocacy efforts at
www.thearcny.org



The Arc[®]
New York

PROVIDING PEOPLE
WITH DISABILITIES THE
**ORDINARY &
EXTRAORDINARY
OPPORTUNITIES
of Life!**

LOCAL IMPACT

- The Arc New York provides supports and services to New Yorkers with intellectual and developmental disabilities at **37 local Chapters** across the state
- Local Chapters are the backbone of direct support for more more than **60,000 individuals** and families
- **30,000 dedicated Chapter staff** deliver essential supports & services 24 hours a day, 7 days a week
- **30 percent** of New Yorkers with I/DD are served by The Arc New York

STATEWIDE SUPPORT

- The Arc New York is the family-led, statewide organization that supports and connects local Chapters, drawing on a rich network of expertise to realize our unified mission
- The Arc New York provides Chapters with programmatic, regulatory, financial, legal, human resources, communications, advocacy, and other supports, strengthening local services with statewide resources, data and best practices
- NYSARC Trust Services and The Arc New York Guardianship program provide direct financial and decision-making supports to individuals, families and Chapters
- Our **70-year history** and **100,000 members** amplify our advocacy with a legacy of influence and a powerful collective voice

WE ARE STRONGER TOGETHER!

thearcny.org



@thearcny

BY THE NUMBERS

The Arc New York provides **30 PERCENT** of all services to New Yorkers with developmental disabilities

For people with I/DD across the state, that means:

60,000	Individuals supported
7,500	Residential opportunities
26 MILLION	Hours of Residential support
750,000	Hours of employment support
10 MILLION	Hours of day programs



The Arc New York contributes more than **\$2.5 BILLION** annually to the New York state economy

33,000	Jobs created through direct employment
\$1.3 BILLION	Employee salaries & benefits
\$787 MILLION	Economic activity generated by employee & vendor spending
\$394 MILLION	Goods & services directly purchased to support The Arc New York operations
\$70 MILLION	Capital spending on buildings and equipment
\$350 MILLION	New York state tax revenue generated

In **EVERY COUNTY** of the State

Chapters of The Arc New York positively impact the lives of people with developmental disabilities and their families through residential supports, skills building, community engagement, vocational development and recreational pursuits



The Arc
New York

Medicaid and other government support provides **90 PERCENT** of the funding for these vital services.

Learn more about what we do, and how you can help preserve essential services for New Yorkers with I/DD at thearcny.org

Supporting the Direct Care Workforce Campaign Overview

Background

As part of The Arc New York advocacy and efforts to support our Direct Support Professionals (DSPs) and overall workforce investment, we are engaging in a continued conversation with our congressional representatives encouraging them to support the [Better Care Better Jobs Act \(BCBJA\)](#) introduced in June. This legislation would include a major investment of \$400 Billion for states to expand access to Medicaid home and community based services (HCBS) and addresses the decades-long workforce crisis and our current emergency.

However, this historic investment is in danger of not being fully supported. In fact, it was recently reported that HCBS might receive a fraction of what President Biden initially proposed in his care economy infrastructure plan. As such, we must be diligent through the end of summer and through the fall to ensure that the entire \$400 billion package is included in the upcoming budget reconciliation resolution.

Support Investment in the I/DD Direct Care Workforce

Voluntary providers of supports and services for people with intellectual and developmental disabilities (I/DD) are facing a critical workforce shortage, which needs immediate action by our federal representatives. In particular, we ask that they fully endorse the BCBJA, which will pave the way for much needed resources for the direct care workforce and beyond.

It is absolutely necessary that we secure adequate government funding to pay our DSPs a wage commensurate with their ability, experience, and performance. If we do not, programs could be reduced or eliminated due to lack of staffing, and many years of progress toward community integration, choice, and deinstitutionalization will be lost. We have already seen valuable DSPs leave the field due to the hardship they face. They are our front-line essential workers and deserve more.

Throughout the COVID-19 pandemic, DSPs have conducted themselves with the utmost professionalism, adapting to ever changing government guidance, and new requirements. They are at the forefront of this crisis more than any other, adapting in ways that demonstrate their dedication to the individuals they serve.

The Arc New York Advocacy Plan

- The BCBJA operationalizes the proposed \$400 billion care economy infrastructure plan proposed by President Biden. It is our goal to engage and inform our congressional representatives about this and other opportunities to support workforce initiatives, as well as policies beneficial to individuals with I/DD and providers. You can view and share our advocacy update dedicated to this announcement [here](#).
- We created an online [campaign](#) for distribution through social media and email lists. The target audience is our federal representatives in the Senate and House of Representatives. Knowing how our advocates hear about campaigns and where they take action is important, so please consider using the specific links below. Both link to this campaign.
 - General Link: <https://p2a.co/1liesUu>
 - Social Media Link: <https://p2a.co/OTp4ZDL>
- We would also like to meet directly with our federal representatives and/or staff. The goal is to educate, but also understand the level of support we can expect from each legislator and their position on long-term DSP workforce and HCBS investment. Ask that question.
- If legislators are not available for our initial meeting, we will work to plan a future engagement through a site visit or virtual fly in.
 - Involving families and self-advocates is a great way to give them a voice, while also connecting legislators to their constituents
- The Arc New York state office can help coordinate NYS and congressional meetings through [Philip Aydinian](#), Director of Governmental Affairs.
 - Political geography includes multiple counties and/or legislators, depending on your Chapter's location. In many cases we can maximize impact if we all work together.
 - Many congressional and state offices require a list of attendees, affiliation, home address, and topic(s) to be discussed
 - Identify constituents within the district. It is impactful and important.
 - Highlight fiscal and social impact across the local community and political district
- Regional public media events are being planned. If you are interested in hosting or participating, please let [Philip Aydinian](#) or [Kate Geurin](#) know so we can appropriately coordinate and provide necessary support
- When you reach out to your legislators through calls, in person, or virtual meetings, please complete this [short survey](#) so we can track the impact of this initiative. It also helps us reach back out to legislators and build on the foundation you have laid.

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.

Supplemental Talking Points when Meeting with State Representatives

STOP THE CUTS. RAISE THE WAGE.

FUND THE FUTURE!

Stop the cuts

- Residential and therapeutic leave cuts (“5/1 cuts”) undermine any investments made in the FY 2021-22 budget
- COVID-19 has devastated providers with unexpected costs and vastly impacted their ability to retain and attract staff
- NYS finances and the influx of federal dollars make cuts unnecessary at this time

Fund a living wage

- These are not minimum wage jobs, but in many cases, they pay at or just above minimum wage
- We need to recognize the skills required for these jobs
- Support a federal job classification/designation for the field to open the door for targeted actions to support the field

Invest in the future

- The field has not been supported with adequate investment to help keep up with ever-increasing costs.
- More than a decade of systemic underfunding has destabilized our system of essential supports and services for New Yorkers with I/DD
- We need regular investments to ensure that provider agencies are not constantly faced with being underfunded and at risk of crisis.
- We require consistent investments to retain our talented and dedicated staff, while attracting new people committed to investing in the lives of the people we support.

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.

Education and groundwork for budget asks for state legislators:

- Voluntary providers of supports and services for people with intellectual and developmental disabilities (I/DD) are facing a critical workforce shortage, which needs immediate action
- We will follow up with specific funding requests soon as the Executive Budget starts coming together (September would be the earliest we have specific dollar amounts)
- The request will be multi-year. We anticipate it will require ongoing investment in the field to redress the inequities of the past.
- The goals will be three-fold:
 - Bring voluntary providers' wages at least in line with state-operated salaries
 - Commitment to a plan that will result in raising the field to a living wage, as we had proposed under previous campaigns
 - ANY funding must be real – new dollars – and not just moving money from other parts of the OPWDD budget.

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
- 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

Support the Better Care Better Jobs Act and I/DD Direct Care Workforce

Template Letter

My name is [advocate] and I am a constituent and supporter of New Yorkers with intellectual and developmental disabilities (I/DD). They are our family, friends, loved ones, and members of our community. Right now we need your help to support them with dedicated and sustainable workforce funding.

The repercussions from the COVID-19 pandemic are still being felt as providers of home and community based services (HCBS) face a severe shortage of Direct Support Professionals (DSP) and few additional resources by which to recruit and retain staff. A recent survey conducted by New York Disability Advocates (NYDA) found that 25% of DSP positions are currently vacant statewide – a 75% increase in vacancy rates since pre-pandemic levels. Ninety-three percent of providers saw a decrease in job applicants this year, and 48% of providers were forced to close or reduce programs due to lack of staff. This is not just a looming crisis; it is an emergency.

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 workers – the majority of whom are women – have been underpaid and undervalued for too long. Caring for people with complex needs is a rewarding yet challenging job, which requires ongoing training, high-level of responsibility, and skill.

For these reasons we are asking you to sponsor the Better Care Better Jobs Act (BCBJA), sponsored by Senators Bob Casey and Ron Wyden and Representative Debbie Dingell. This is a once in a generation chance to create the care economy infrastructure that New Yorkers need, while providing increased wages, career ladders, and opportunities for DSPs, who are the backbone of the system of supports and services that people with I/DD and their families depend on. Having a 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.

Expanding HCBS would help eliminate waiting lists, and pave the way for much deserved DSP compensation, recognition, and career paths. Additional pieces of legislation to sponsor are S.1437 – Recognizing the Role of Direct Support Professionals Act, which would establish a Standard Occupational Classification (SOC) for DSPs, a big stepping stone towards acknowledging their true

scope of work, and H.R.2999 – Direct Creation, Advancement, and Retention of Employment (CARE) Opportunity Act, which provides resources to support and grow our workforce

I cannot stress enough the importance of investing in our care infrastructure and your support of the Better Care Better Jobs Act. Not only will these funds go directly into our local economy, but it will vastly improve the quality of life for DSPs and the individuals they support.

Thank you for your time and I look forward to your response.

Sincerely,

[Advocate Name]

2021 NYDA Workforce Survey

NYDA provider organizations recently conducted their annual statewide workforce survey. The 2021 survey results reflect the period from January 1 through April 30 and capture data from 127 providers responsible for well over 60% of statewide disability services program funding. This year, a few new questions were added to capture the impact of COVID 19 and the workforce shortage on people who receive services and the staff who provide those services.

SURVEY RESULTS	
Total Survey Responses	118
Average Vacancy %	25%
Region 1	18.29%
Region 2	27.33%
Region 3	25.77%
Region 4	27.61%
Statewide Average	24.75%
Change in Average Statewide Staff Vacancy Rate from pre-pandemic through January 1, 2021 – April 1, 2021	74.3%
Staff Turnover Ratio – Statewide	11.90%
Statewide Agency Staff Vacancy Rate Over 30%	23.72%
Agencies reporting senior staff had to cover shifts due to staffing shortages from 1/1/21 – 4/1/21	69.2%
Agencies reporting that their agency had to close programs or reduce operations due to staffing shortages	47.9%
Agencies reporting programs not opened due to staff shortages	39.32%
Agencies reporting a decrease in job applicants	93.16%

DSP CRISIS EVENT MEDIA ADVISORY TEMPLATE

[INSERT IMAGE OF ORGANIZATION LOGO HERE]

FOR IMMEDIATE RELEASE

CONTACT: [Media Contact Name] | [Media Contact Email] | [Media Contact Phone Number]

*****MEDIA ADVISORY FOR [INSERT DATE OF EVENT]*****

**[ORGANIZATION(S)] TO HOST [EVENT DESCRIPTOR] TO ADDRESS STAFFING
CRISIS OF DIRECT SUPPORT PROFESSIONALS FOR I/DD INDIVIDUALS**

To Address This Emergency Head On, [Organization(s)] will be Joined [List Max Five Speakers and Attendees in Order of Importance] to [Include What Will Be Discussed/Spoken at Event]

[Insert the date, time and location of where your event will be held]

City, NY— New York’s system of supports and services for individuals with intellectual and developmental disabilities (I/DD) is in the midst of an emergency due to an inability to recruit and retain Direct Support Professionals (DSPs), who are the backbone of the system. This staffing situation has been worsening for years without adequate funding, only to be compounded as a result of the COVID-19 pandemic.

DSPs work with individuals with I/DD helping them live fulfilling lives, make choices, and live and work in their communities. The DSP workforce emergency affects continuity and consistency in the lives of the people being served. DSP workforce instability also affects provider agencies, as they struggle to maintain an adequate workforce and ensure positive outcomes for the individuals to whom they provide critical supports and services.

[Insert 2–4 sentences on the details of the event. Include who will be speaking and attending and what they will be discussing.]

RSVP: [Include who attendees should contact to RSVP or include link to event registration if online]

WHO: [In order of rank/seniority/importance list who will be in attendance]

WHEN: [Insert date and time of event]

WHERE: [Insert location of event]

###

About [Organization]

[Insert boilerplate of organization(s). Note, there may be more than one boilerplate depending on how many organizations are involved in the event.]

DSP CRISIS EVENT PRESS RELEASE TEMPLATE

[INSERT IMAGE OF ORGANIZATION LOGO HERE]

FOR IMMEDIATE RELEASE

CONTACT: [Media Contact Name] | [Media Contact Email] | [Media Contact Phone Number]

[ORGANIZATION] HOLDS [EVENT DESCRIPTION]

[Organization] was Joined by [List Attendees in Order of Importance] to [Describe What Was Discussed at Event]

[Include Any Newsworthy Points from Event Here]

City, NY— Today, [organization(s)] hosted a [event descriptor] to discuss the state’s workforce crisis of Direct Service Professionals (DSPs) who provide support and services to individuals with intellectual and developmental disabilities (I/DD) and who are the backbone of the I/DD support system. The event was attended by [include speakers and attendees] who raised awareness regarding the workforce crisis the I/DD sector is facing to identify solutions. [If available include sentence leading to link of video or news article of event.]

[Insert quote from lead hosting organization speaker’s OR from most important speaker’s event remarks.]

[Insert quote from DSP worker or another important speaker from their event remarks.]

The results of a recent survey [insert link to survey memo] conducted by New York Disability Advocates found that nearly 74% of DSP provider agencies experienced a higher vacancy rate than before the pandemic. Nearly half of surveyed agencies reported that they had to close programs or reduce operations due to staffing shortages. Unfortunately, without adequate funding provider agencies cannot provide wages competitive with sectors such as food service and retail to entice new workers.

[Insert quote(s) from additional speakers at the event.]

[Insert 4–5 sentences on what was discussed at the event. This paragraph should lead into:]

[Additional quote from another event speaker]

The DSP workforce emergency affects continuity and consistency in the lives of the people being served. DSP workforce instability also affects provider agencies, as they struggle to maintain an adequate workforce and living wage for the 97,000 DSPs and ensure positive outcomes for the I/DD individuals to whom they provide critical supports and services.

###

About [Organization]

[Insert boilerplate of organization(s). Note, there may be more than one boilerplate depending on how many organizations are involved in the event.]



I/DD WORKFORCE EMERGENCY

**New York Disability Advocates Report
JULY 2021**

NEW YORK
**DISABILITY
ADVOCATES**
Life. Supported.

The New York Disability Advocates recently conducted a statewide workforce survey to quantify the reports from provider agencies highlighting increasing and significant staff vacancies among their Direct Support Professionals (DSPs).

DSPs are a vital part of New York’s “care economy,” and are the backbone of the system of supports and services for people with disabilities. DSPs are employed by the not-for-profit provider agencies and directly by individuals with disabilities to provide vital supports and services in group residential settings, independent apartments and homes, and in recreational and therapeutic day support settings.

The role of a DSP is not an easy one, requiring a high degree of responsibility, skill and compassion.

DSPs are essential to ensuring that individuals with intellectual and developmental disabilities (I/DD) are safe, lead fulfilling lives in their communities, and receive attention for complex medical and therapeutic needs.

The 2021 NYDA survey results capture data from January 1 through April 30, 2021 and includes data from 118 providers agencies which represent approximately 60% of statewide voluntary program funding for the field. The survey showed that statewide, provider agencies have an average 24.75% vacancy rate for direct care staff. The full survey data topline are as follows.

SURVEY RESULTS				
Total Survey Responses				118
Statewide Average Vacancy %				24.75%
Regions¹				
Region 1 (Downstate) 18.29%	Region 2 (Hudson Valley) 27.33%	Region 3 (Upstate Metro) 25.77%	Region 4 (Rest of the state) 27.61%	
Change in Average Statewide Staff Vacancy Rate from pre-pandemic through Jan 1, 2021 – Apr1, 2021				74.3%
Staff Turnover Ratio – Statewide				11.90%
Statewide Agency Staff Vacancy Rate Over 30%				23.72%
Agencies reporting senior staff had to cover shifts due to staffing shortages from January 1, 2021 - April 1, 2021				69.2%
Agencies reporting that their agency had to close programs or reduce operations due to staffing shortages				47.9%
Agencies reporting programs not opened due to staff shortages				39.32%
Agencies reporting a decrease in job applicants				93.16%

1. Region definitions: https://www.health.ny.gov/health_care/medicaid/rates/mental_hygiene/doh-owpdd_regions.htm

Notably the survey showed a 74.3% increase in the staff vacancy rate from pre-pandemic levels.

Furthermore, nearly 70% of agencies statewide reported supervisory staff needing to cover shifts as a direct result of staffing shortages. The results of the NYDA survey paint a dire picture for the I/DD service delivery system, which necessitates swift action by the State of New York to adequately address the current emergency and to ensure individual's safety and the future viability of the system.

On June 2nd, NYDA hosted a Workforce Summit that brought together more than 700 participants including representatives from provider agencies and state government, service recipients, family members and those who work in direct support positions. They discussed the current emergency and developed ideas and strategies for a comprehensive approach and to provide a roadmap for the State and providers, as partners, to respond to the workforce emergency and provide long term stability.

At the Summit, participants cited recruitment, retention, fiscal and regulatory relief as the main areas of focus. However, the common theme that was discussed throughout is the need for increased funding from the state to support higher wages for DSPs. With OPWDD receiving approximately \$800 million in enhanced Federal Medical Assistance Percentage (eFMAP) for home and community-based services (HCBS) as part of the recently enacted American Rescue Plan Act, NYDA believes that this funding must be utilized as a down payment to increase wages for direct care staff. Additionally, the state must commit to increasing funding and rates to support a living wage for staff.

New York must look to the steps that the federal government is taking to recognize the importance of the care economy, with the introduction of the Better Care and Better Jobs Act, which would vastly expand the Medicaid HCBS program. The legislation forms the basis of President Biden's \$400 billion commitment to expand access to HCBS and raise the wages of direct support professionals in his American Jobs Plan.

The following recommendations have been identified as critical to addressing the emergency.

ESTABLISHMENT OF A LIVING WAGE:

In 2014, New York's Governor Andrew Cuomo announced the intent to increase the state's minimum wage. Provider associations across New York and other advocates who support people with intellectual and developmental disabilities came together to respond to this proposal. While they supported an increase in the state's minimum wage, they worried that DSPs would be

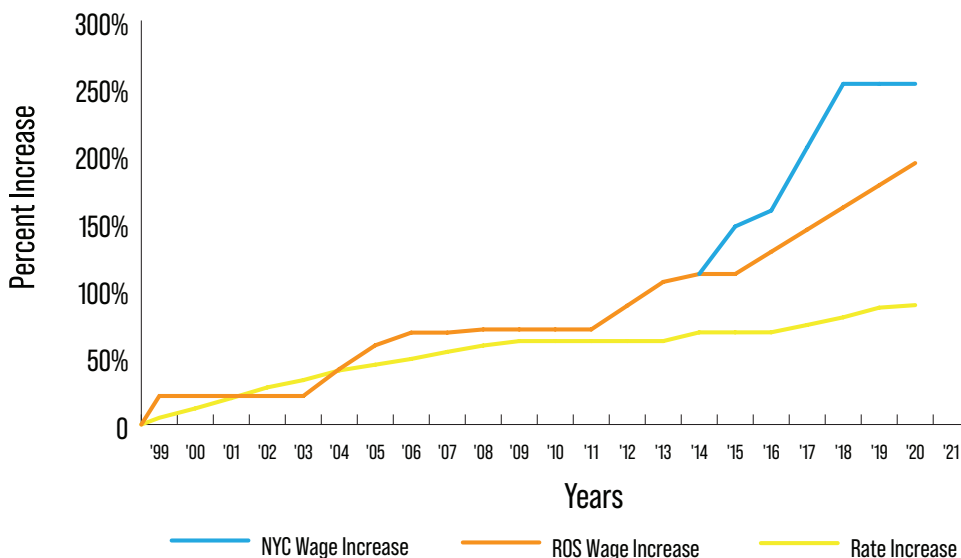
left behind in two ways: first, direct support personnel, whose responsibilities far exceed those of entry-level minimum-wage employees, would lose any ground gained toward professionalism; and second, the state may not even increase current DSP rates of pay to match the progressive increases intended for the general minimum wage targets.

By 2016, the state legislature adopted a multi-year, phased-in minimum wage of \$15 per hour, effectively designating DSPs as minimum wage workers. More concerning, the enactment of the \$15 per hour minimum wage for fast food worker has created a significant toll on upstate providers.

To address this, the statewide provider agencies began the bFair2directcare campaign, with the goal of securing wage increases for direct care staff, but the state imposed a Budget Neutrality Factor (BNF). Although funding was allocated to fund the increase, the state was able to reduce rates through across the board rate actions that ultimately negated the funding increases and essentially created an unfunded mandate.

Further compounding the situation for provider agencies has been the lack of inclusion of the statutory Cost-of-Living-Adjustment which has been notwithstanding more than a decade. Unlike for-profit entities that have the ability to raise prices, not-for-profit providers have only been able to pay rates as afforded by the funding that is provided by OPWDD, which has caused stagnation in the wages. These actions have directly resulted in the current, nearly 25% vacancy rate.

Therefore, it is essential that OPWDD be required to annually calculate a living wage for staff and adjust provider agencies' rates accordingly.



1: NYC minimum wage increases reflect schedule of large employers with 10 or more employees

2: Long Island and Westchester minimum wage schedule is not broken out separately for the purposes of this chart

Additionally, payments must not be subject to a budget neutrality factor, which historically has taken funding away from provider agencies.

Provider agencies across the state have already taken action to increase wages, without any additional funding from the State to fund these increases, which must be addressed to ensure the viability of the voluntary section to ensure that services will be available and that NYS is able to meet its constitutional obligation to the I/DD community.

RECRUITMENT

Provider agencies have faced challenges in recruiting and retaining staff as a direct result of the statewide minimum wage increases, the lack of annual increases for more than a decade, combined with a state rate system that has resulted in certain providers being reimbursed at below their actual costs, and all providers not receiving sufficient trend factors or other increases to support basic cost of living increases. This issue has been compounded by the COVID-19 pandemic, which caused a significant decrease in the number of applicants for direct support positions in the I/DD service delivery system as well as early retirements and other exodus from the positions in the field.

Through the first quarter of 2021, 93% of provider agencies reported a decrease in the number of applicants as compared to previous reporting periods.

To address the recruitment challenges that agencies are facing, the following proposals should be implemented.

CREATION OF THE DIRECT SUPPORT PROFESSIONALS (DSP) STANDARD OCCUPATIONAL CLASSIFICATION

The U.S. Bureau of Labor Statistics (BLS) classifies workers into occupational categories called the Standard Occupational Classification (SOC) for the purpose of collecting, calculating, or disseminating valuable wage and occupation data. All workers are classified into one of 867 detailed occupations according to their occupational definition. A discrete SOC does not exist for DSPs, which means strong wage and occupation data is unavailable and such critical workforce data is not accurately captured.

BLS combines DSP data with that of Personal Care Assistants and Home Health Aides which does not accurately reflect the profession. With the current DSP workforce shortage in New York, a discrete DSP classification will yield the appropriate data to assist states and federal agencies better understand a workforce that is facing increased demand at a time when recruitment and

retention are low and turnover is high. The establishment of a DSP classification will also further advance the “professionalization” of the role.

NYDA believes that stronger federal data on DSPs will help address workforce shortages by providing a more accurate understanding of this profession and assisting advocacy efforts to implement a living wage for DSPs.

Members of NY’s delegation in the U.S. Congress, along with members of the NYS Legislature and the Governor must call upon the Biden Administration and the federal Bureau of Labor Statistics to authorize a discrete Standard Occupation Classification for DSPs.

BOCES HIGH SCHOOL PROGRAM

To address the need for DSPs, a pilot program was initiated in the Capital Region to introduce the direct support profession to new potential workforce candidates.

Individuals enrolled in the pilot program through the Capital Region BOCES are provided work-based learning opportunities, job mentoring and curriculum-based training. The pilot project aligns state education standards with quality DSP training metrics and offers participants six certificates including Nurse Assistant, Home Health Aide, Personal Care Aide, Direct Support Professional, American Heart Association Basic Life Support/CPR and First Aid. The program teaches students the skills necessary for a long-term career of helping people with disabilities live independently in their own communities, in group home settings or in a nursing home.

After successful completion, Program Course Participants are eligible for job placement upon graduation.

The goal of the pilot is to increase the pool of qualified candidates in the direct support profession as one tool to address the workforce shortage. To ensure statewide access to individuals, we recommend that the State establish a transition plan that incorporates providers and education representative’s input with a goal to replicate this program statewide by 2023.

EXPANSION OF THE SUMMER YOUTH EMPLOYMENT PROGRAM

The expansion of the Summer Youth Employment Program (SYEP) would provide an additional avenue to address the shortage of DSPs in the workforce. Currently, Local Workforce Development Boards receive funding through the TANF program for summer youth programs.

Historically, not-for-profits I/DD agencies have worked with individual local Workforce Development Boards to provide a program that is designed to invest in low

income or at-risk-youth by providing academic support, work experience and other extra-curricular services in order to promote high school graduation, post-secondary enrollment and successful entry into the I/DD workforce. The ages of the participants range from 16-18, those entering 11th and 12th grades.

To expand access and increase participation statewide for promotion of the I/DD workforce, we recommend a statewide program in the direct support role be established and promoted across the State as an additional avenue to address the shortage of DSPs.

STATEWIDE MARKETING CAMPAIGN FOR CAREERS AS A DIRECT SUPPORT PROFESSIONAL

In recognition of the workforce emergency that exists there is a need to raise public awareness of career opportunities in the I/DD service delivery system.

By partnering with New York State to create and implement a statewide ad campaign aimed at educating individuals on rewarding careers in the I/DD service delivery system, awareness will drive an increase in job applicants for direct support roles at provider agencies.

This campaign should highlight the benefits and the incentives that exist for individuals who work in these roles and provide awareness of the sector and the individuals that are served.

RETENTION

For years, the I/DD service delivery system dealt with high staff turnover in the DSP role. According to a 2017 American Network of Community Option and Resources (ANCOR) report on DSPs, the high turnover and recruitment difficulties in the I/DD field is damagingly disruptive to individuals with I/DD and constitutes a public health crisis.

The ANCOR report indicates low wages, lack of public awareness and lack of opportunities to advance their careers as just some of the reasons these dedicated workers leave their jobs. Therefore, it is vital for the State to aggressively develop and implement strategies that will significantly reduce turnover and provide pathways for individuals to stay in this field.

To address the systemic challenges that provider agencies have faced in retaining individuals in these vital direct support positions, the following strategies are recommended:

DSP CREDENTIAL AND CAREER LADDER PROGRAM

To incentivize individuals to remain in DSP roles, there is the need for a multi-pronged approach to establishing a “career ladder/lattice” with the goal of reducing turnover by providing additional training and opportunities, which will improve quality outcomes for individuals being served and increase pay for individuals who remain in the field and wish to further their careers.

DSP CREDENTIAL

NYS must act immediately to implement a multi-tiered credential program for DSPs with a hybrid model of learning methods tied to increased pay for individuals completing each tier of the credential.

Credentialing and certification programs are strong solutions to consider in closing the wage gap that currently exists in New York’s I/DD sector. Such programs provide targeted opportunities for people to master specialized content areas in professions that require targeted skills and practical responses. A direct support professional credentialing program is a key tool to strengthen the workforce by providing knowledge and skills, recruit and retain qualified staff and create the bridge between skill building and increased wages.

A clear rationale exists in New York for advancing a statewide, voluntary credentialing program for DSPs with evidence that a robust process will strengthen and increase the pipeline for DSPs, value-based wage enhancement and career growth and advancing the DSP skill and knowledge to reach accountable goals for better quality and affordable supports and services.

By adopting a multi-tiered credential model, which combines on-line, classroom and work-based learning, including a number of successful and well-established credentialing programs, New York State will be able to increase DSP tenure, job satisfaction and provide a career path.

CAREER LADDER/LATTICE

New York State should implement a statewide Career Ladder Program for DSPs, which will provide a pathway to an associate’s degree in the human services field for current DSPs who have participated in the credentialing program and offer it at no cost to the participants.

The program should provide job-specific higher education and career development to frontline workers in health, education, and human service occupations. Some examples include a degree in:

- Community residence management

- Developmental disabilities
- Psychology
- Education
- Human Services/Social Work
- Nursing
- Physical Therapy Assistant
- Occupational Therapy Assistant.

Existing pilot and demonstration programs have been proven to increase the retention of direct care workers, improve their job performance, and strengthen the quality of care received by people supported and their families. These existing programs can be used as the framework for a statewide career ladder program, which could also leverage the SUNY and CUNY for All program that was recently expanded to include OPWDD.

For those with family and/or financial constraints, a one-year certificate program in community residence management or disability studies may also be offered.

ESTABLISH A PERSONAL INCOME TAX CREDIT FOR DSPS

In recognition of the workforce emergency that exists in the I/DD provider community, there is a significant need to provide incentives to recruit and retain employees who choose to work in the I/DD field. This is especially critical with the rising minimum wage, increasing wages paid by large employers, like Amazon and Costco, and the increasing fast food statewide minimum wage. All of this exacerbates the need to provide incentives for individuals to join and stay in direct care roles.

We recommend that a \$2,500 refundable personal income tax credit be established for individuals who are employed by or contracted by not-for-profit provider agencies who are in 100, 200 or 300 direct care positions providing supports and services to individuals with I/DD. This tax credit could phase out on incomes over \$50,000 and could be capped on individuals with incomes in excess of \$100,000.

FISCAL

OPWDD is currently undertaking a rate setting methodology redesign that will be used as the basis of payment rates to provider agencies moving forward.

As part of this process, it is essential that the rate methodology include provisions to ensure that the new rates are adequate to pay direct support staff a living wage, without this specific consideration as part of the

rate, the current issues facing the field will persist and amplify.

Furthermore, should a regional average approach be implemented, any proposed rate structure must not take funds away from providers for current workforce expenses; forcing providers to lose dollars simply because they pay employees a living wage or a wage above the regional average is not justifiable and will further undermine the voluntary service delivery system, leading to higher costs to the State's Medicaid program. Efforts to establish a new reimbursement methodology must recognize and appropriately value the workforce, both those new and those with more years in the field. It is essential for the state to incentivize providers to invest in DSPs in order to reach a living wage and close the wage gap between the voluntary sector and the state-operated system.

Finally, the State must commit to ensuring that the rising costs of operations are considered and funded on an annual basis.

REGULATORY REFORM

While “regulatory reform” is a buzz term that is thrown around often, we recognize that this process is complicated and time consuming with both federal and state mandates to consider. To truly take meaningful steps to reform/streamline the service system, significant changes must be allowed – and a true partnership between the provider community and the State must exist to advance many proposals. Furthermore, the State must truly be receptive to removing redundant, irrelevant and/or ineffective rules that cost the system time and money. The state must also refrain from implementing new costly rules and administrative memoranda and must put in place a process of review with providers prior to implementation. Similarly, smoothing the path to expanded use of programs and technology that will mitigate the dependence on staff-based programs should be a priority. Here are some of the ideas that warrant further exploration:

INCIDENT MANAGEMENT REPORTING REFORMS

The Office for People with Developmental Disabilities (OPWDD) incident management reporting, investigation, and review processes include excessive administrative duties that have reduced the provider community's ability to focus on the improvements in quality of life for people with I/DD due to occupying and exhausting limited provider resources.

These processes have become focused on presentation over content with providers spending time completing lengthy and often duplicative forms, inspecting incident

and investigation report formats, and responding to numerous state requests to correct clerical errors in an effort to conform to inflexible standards. The administrative duties have to be examined and streamlined to require the reporting, recording and submission of only the most critical information aimed at reducing the recurrence of incidents.

The state incident management oversight functions are redundant across both OPWDD's internal units, the New York State Justice Center for the Protection of People with Special Needs, and expectations of provider Incident Review Committees (IRCs). Incidents are reviewed several times by OPWDD's Incident Management Unit, Bureau of Program Certification (BPC), Mortality Review Unit, the provider's IRC and ultimately the New York State Justice Center. Each review produces additional requests for administrative response, often on incidents several years old. The oversight function needs to be examined and streamlined to limit the parties responsible for review and requests for additional information.

Interoperability between state incident management information systems remains unavailable. This creates additional duplicative administrative reporting and response duties. OPWDD's Incident Reporting Management Application (IRMA), the New York State Justice Center's Web Submission of Investigative Report (WSIR) and Administrative Action Reporting Mechanism, The New York State Incident Management and Reporting System (NIMRS) for the Office of Mental Health (OMH) and the New York State Department of Health (NYS DOH) Incident Reporting and Management System (IRAMS) are just some of the state systems that providers must report incident information into, often for the same event.

New York State must place paramount concern on the burden on workers, including increase on workload, that regulations and inefficient processes place on the disability workforce. The negative impact the Justice Center adds to those in the disability field needs further attention on how best to mitigate the Center's activities on good employees who what are almost entirely unfounded allegations to deal with. Burdensome regulations and the unique problems the Justice Center brings to the field are State-created challenges that must be minimized.

The state must examine the reporting systems and streamline them by creating interoperability or a singular statewide record keeping system.

EXPANDED USE OF TECHNOLOGY

Currently, there are support monitoring systems, location monitoring devices, tele-support services and devices, etc. that would enable people across the state to live more independent lives if program rules and funding could be more readily accessible. Telehealth triage systems, centralized live-in staffing with support monitoring systems, and other programs have proven successful on a pilot basis in New York and have successfully been used beyond piloting in other states – we need to allow expansion of these models that reduce reliance on staff. We propose that a provider-led group be tasked with working with families and current users of the system to develop a detailed proposal for technology-based changes within OPWDD's system by the fall of 2021.

STREAMLINE MEDICATION ADMINISTRATION TRAINING

Work with providers to identify successful models for implementation of online and minimal in-person training options to ensure medication administration proficiency. Streamline training to target the reduction of common medication administration errors which would both reduce the training time for staff and focus on the essential information they need to keep the people they support safe.

ACCELERATE BACKGROUND CHECKS

Streamlined/cross-agency background checks through a state centralized data warehouse must move forward. The State should no longer point to federal or state barriers – remove the barriers and implement one NYS application for staff, then work with the agencies to provide the data each needs for its respective background check requirements.

SURVEY RELIEF – DURING PERIODS OF STATE OF EMERGENCY

The idea of a risk-stratified approach to surveys is a welcome first step, but there is much work to be done to recognize the staffing shortage's impact on staff who often are pulled away to respond to/participate in program surveys by the state. Particularly in staffing emergencies, we recommend stepped down options for the State's survey obligations to be implemented.

Recognizing the Role of Direct Support Professionals Act

Sponsored by Senators Maggie Hassan (D-NH) & Susan Collins (R-ME)

The Problem:

Direct Support Professionals provide integral support to individuals who experience disabilities, such as assisting with communication, providing on-the-job coaching, and helping with daily living needs. These workers play a critical role in helping ensure that individuals who experiences disabilities can live independently and fully participate in their communities. But right now, there aren't enough workers to fill this critical need. Home- and community-based service providers struggle to recruit and retain Direct Support Professionals. A 2016 study by the National Core Indicators showed that Direct Support Professionals had a national turnover rate of 45 percent.

A lack of sound data compounds the problem. Federal agencies use data collected through the Bureau of Labor Statistics Standard Occupational Classification system to analyze workforce trends, but this system does not provide an accurate picture of current Direct Support Professional workforce challenges. This system classifies Direct Support Professionals under the broader category of "home health care aide," which includes all home health care occupations. As a result, it is impossible to accurately track and report workforce trends for Direct Support Professionals, often resulting in the underreporting of workforce needs and regional workforce shortages.

The Solution:

This bill would direct the Office of Management and Budget to revise the Standard Occupational Classification 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.

This legislation is supported by: the American Network of Community Options and Resources (ANCOR), the National Alliance for Direct Support Professionals (NADSP), the Arc of the United States, Autism Speaks, Autism Society of America, ABLE NH, the American Association on Health and Disability, Autistic Self Advocacy Network, Association of People Supporting Employment First (APSE), CommunicationFIRST, Easterseals, the Jewish Federations of North America, Justice in Aging, Lutheran Services – American Disability Network, National Association of Councils on Developmental Disabilities, National Association of State Head Injury Administrators, National Down Syndrome Congress, United Spinal Association, Cure SMA, TASH, National Dance Therapy Association, and the National Brain Injury Association.

For more information or to cosponsor, please contact Brittany Matthews (Brittany_Matthews@hassan.senate.gov) or Michael Mets (Michael_Mets@collins.senate.gov).

BETTER CARE BETTER JOBS ACT (S. 2210)

A Historic Investment in the Care Economy

**Led by Chairman Casey, Chairman Wyden and Leader Schumer
with Chair Murray and Senators Duckworth, Hassan and Brown**

President Biden's American Jobs Plan includes a historic investment in Medicaid home and community-based services (HCBS). These critical services enable seniors and people with disabilities to remain in their homes, stay active in their communities, and lead independent lives. The President's proposal will expand access to good-quality care, lead to better pay and benefits for workers, enhance quality of life for families, and help create middle-class jobs. This investment creates enhanced funding to strengthen long-term care today and for the future, building on the \$12.7 billion short-term HCBS funding that passed as part of the American Rescue Plan.

The COVID-19 pandemic has highlighted the urgent need to ensure all Americans have the option to receive quality, long-term care in the setting that best meets their needs and preferences. The vast [majority of Americans](#) would prefer to receive services and supports at home. Today, [over 3.5 million](#) older adults and people with disabilities receive Medicaid HCBS. Though all states provide coverage for some HCBS services, eligibility and benefit standards vary, leading to significant variation and gaps in coverage. Some states cap the number of individuals who may receive services, which has left almost [820,000 Americans](#) on wait lists.

The President's proposed investment also prioritizes wage and benefit increases for the workers who provide these services. Nationwide, home care workers—a majority of whom are women and people of color—earn a median wage of [\\$12 per hour](#). Roughly [18 percent](#) of these workers live in poverty and many receive [few or no benefits](#). This low compensation, paired with the difficulty of the work, results in exceptionally high turnover rates among direct care workers, often estimated [between 40 and 60 percent](#).

The **Better Care Better Jobs Act** carries forward President Biden's bold vision. Specifically, the bill would:

- **Enhance Medicaid funding for 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. To receive these dollars, states must:
 - **Strengthen and expand access to HCBS** by expanding financial eligibility criteria for HCBS to federal limits; requiring coverage for personal care services; expanding supports for family caregivers; adopting programs that help people navigate enrollment and eligibility; expanding access to behavioral health care; improving coordination with housing, transportation, and employment supports; and developing or improving programs to allow working people with disabilities to access HCBS.

- **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; and updating and developing training opportunities for this workforce as well as family caregivers.
 - **Show improvement over time** by demonstrating improved availability of services; reduced disparities in accessing and using HCBS; evidence of competitive wages and benefits for workers; and 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.
 - **Support quality and accountability:** Provide funding to the Centers for Medicare & Medicaid Services to carry out the bill's programs; conduct oversight and monitoring; and offer technical assistance to states participating in the funding opportunities described above. Additionally, participating states would be required to establish state HCBS ombudsman programs to support care quality. The bill would also require all state Medicaid programs to adopt HCBS quality measures.
 - **Facilitate state planning:** Provide 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.
 - **Permanent spousal impoverishment protections:** Permanently authorize protections against impoverishment for individuals whose spouses are receiving Medicaid HCBS.
 - **Make Permanent Money Follows the Person:** Make the Money Follows the Person Rebalancing Demonstration permanent.

Cosponsors: Baldwin, Bennet, Blumenthal, Booker, Cantwell, Cardin, Durbin, Feinstein, Gillibrand, Hirono, Heinrich, Kaine, King, Klobuchar, Leahy, Luján, Markey, Merkley, Menendez, Murphy, Padilla, Peters, Reed, Rosen, Sanders, Schatz, Shaheen, Smith, Stabenow, Van Hollen, Warnock, Warren and Whitehouse

Supporting Organizatons: Allies for Independence, Association of Assistive Technology Act Programs (ATAP), Easterseals, Gerontological Society of America, Indivisible, Inglis, Justice in Aging, Latinos for Secure Retirement, Little Lobbyists, National Council on Independent Living (NCIL), National Academy of Elder Law Attorneys, National Council on Aging (NCOA), National Domestic Workers Alliance (NDWA), Rehabilitation and Community Providers Association, SEIU, Social Security Works, The Arc, Via of the Lehigh Valley and United Cerebral Palsy

Section-by-Section:

Section 1. Short Title and Table of Contents

Section 2. Definitions. Includes definitions for terms relevant to the bill, such as direct care workers and home- and community-based services (HCBS).

Title I – Expanding Access to Medicaid Home- and Community-Based Services

Section 101. HCBS Infrastructure Improvement Planning Grants. Provides \$100 million for states to develop plans to expand access to Medicaid HCBS and strengthen the HCBS workforce. As a part of these plans, states would be required to report on the state’s existing HCBS landscape and describe how they will address gaps and disparities in access and utilization. Such plans would be developed with input from stakeholders through a public notice and comment process. During the planning period, states would continue to receive the level of enhanced federal funding for HCBS provided through the American Rescue Plan. States receiving planning grants must comply with a maintenance of effort that restricts them from reducing eligibility or benefit standards for HCBS.

Section 102. HCBS Infrastructure Improvement Program. Provides states with a 10 percentage point increase in the Medicaid Federal Medical Assistance Percentage (FMAP) for HCBS and an enhanced federal match of 80 percent for administrative activities associated with improving HCBS programs. To receive this enhanced match, states would be required to:

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; and
- Expand access to behavioral health services and coordination with employment, housing, and transportation supports.

Strengthen and expand the HCBS workforce:

- Address insufficient payment rates for HCBS to promote access and improve workforce recruitment and retention;
- Update HCBS payment rates every two years through a transparent process with input from stakeholders;
- Ensure increases in HCBS rates are passed through to workers to improve compensation for direct care workers;
- Ensure rates are incorporated into managed care arrangements; and
- Update, develop, and adopt qualification standards and training opportunities for direct care workers and family caregivers.

Comply with a maintenance of effort requirement that prohibit them from reducing HCBS benefits or restricting eligibility. Beginning in FY 2029, states would have the flexibility to modify such standards if they comply with certain guardrails and receive federal approval.

States may receive an additional 2 percentage point FMAP increase for HCBS for one year if they establish certain models for the delivery of self-directed care. States could establish these programs either directly or by contracting with non-profit entities. Such programs would:

- Register qualified direct care workers and connect beneficiaries with providers;
- Recruit independent providers and train them and beneficiaries on self-directed care;
- Ensure safety and quality of care, such as by conducting background checks;
- Facilitate communication and coordination between the state and HCBS direct care workers, including for matters of public health;
- Support beneficiary hiring of independent providers of HCBS;
- Where applicable, support beneficiaries who wish to hire a caregiver who is a family member or a person with whom they have an existing relationship to provide care; and
- Ensure that program policies and procedures allow for cooperation with labor organizations where applicable in states and that programs remain neutral with regard to organizing.

To receive enhanced federal Medicaid funding for HCBS under this legislation, states must meet certain accountability and quality requirements. Specifically, they must:

- Adopt quality measures for HCBS;
- Designate a state ombudsman program for HCBS;
- Report outcomes to the federal government; and
- After seven years of receiving enhanced funding, demonstrate: increased availability of HCBS, reduced disparities in the utilization and availability of HCBS, evidence that a majority of direct care workers receive competitive wages and benefits, and at least 50 percent of long-term care spending on HCBS.

Section 103. Reports; Technical Assistance; Other Administrative Requirements. Requires the Secretary of the Department of Health and Human Services (HHS) to report on the implementation and outcomes of state HCBS infrastructure improvement programs to expand services and support the workforce. HHS will also provide technical assistance to states implementing these programs. The Secretary of HHS will also work with the Administrator of the Centers for Medicare & Medicaid Services (CMS) and the Secretary of Labor to issue recommendations to strengthen the HCBS workforce, including with respect to how CMS and state Medicaid programs can enforce and support the provision of competitive wages and benefits.

Section 104. Quality Measurement and Improvement. Requires HHS to develop and publish a recommended core set and supplemental set of HCBS quality measures for use by state Medicaid programs. In developing these measures, HHS would be required to collaborate with the Administrator of CMS, the Administrator of the Administration for Community Living, the Director of the Agency for Healthcare Research and Quality, and the Administrator of the Substance Abuse and Mental Health Services Administration in developing these measures, and would be required to receive input from stakeholders.

These measures would be updated annually. All state Medicaid programs would be required to adopt these measures, or alternative sets approved by HHS, regardless of whether they apply for the enhanced funding for HCBS. States would receive an 80 percent enhanced federal Medicaid match for administrative costs associated with these quality measures.

Title II – Other Provisions

Section 201. MACPAC Study and Report on Appendix K Emergency Home and Community-Based Services (HCBS) 1915(C) Waivers. Requires MACPAC to conduct a study on flexibilities leveraged during the pandemic and innovative service delivery models to enhance HCBS access.

Section 202. Making Permanent the State Option to Extend Protection Under Medicaid for Recipients of Home and Community-Based Services Against Spousal Impoverishment. Makes Medicaid HCBS spousal impoverishment protections permanent.

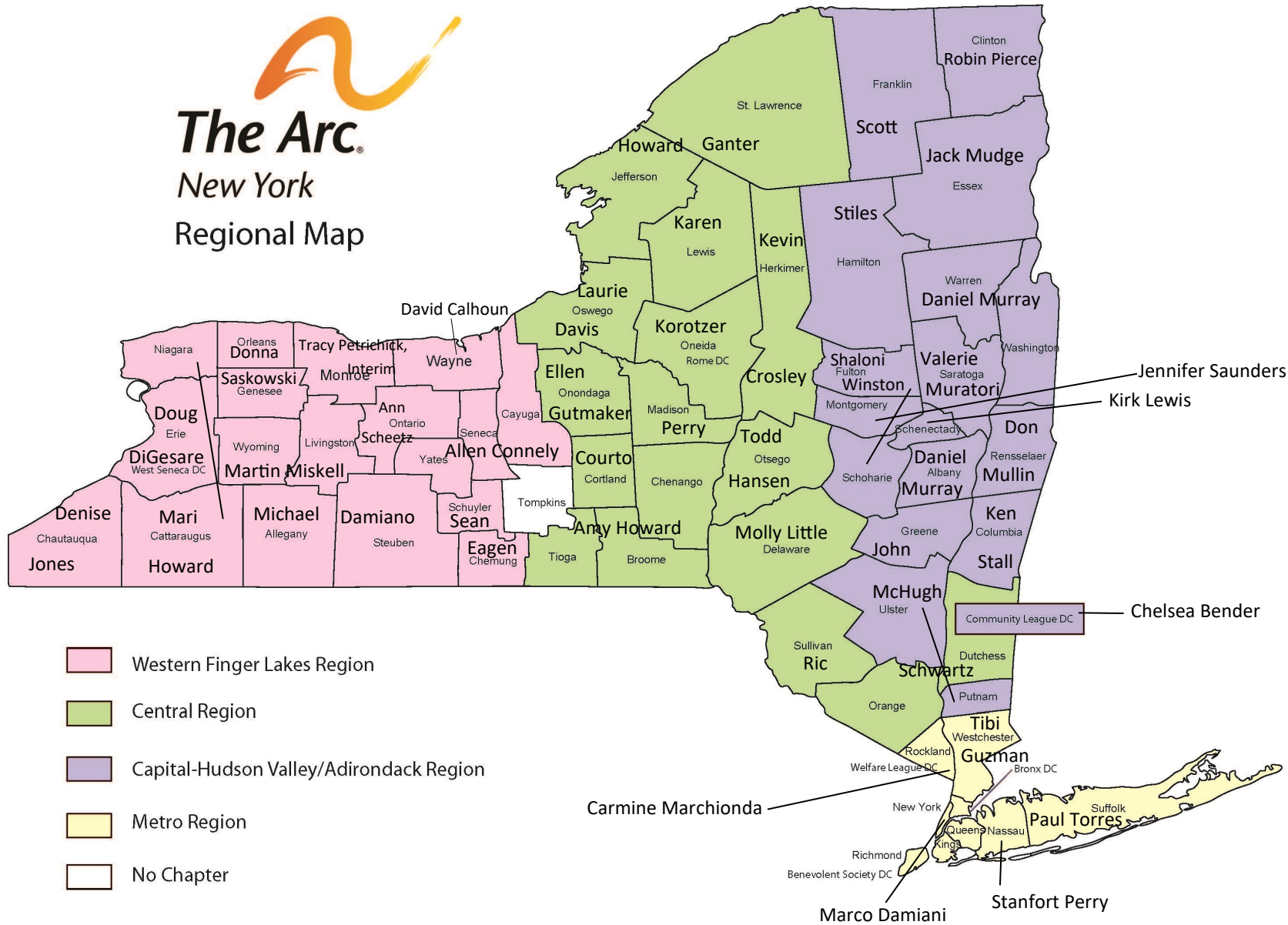
Section 203. Making Permanent Money Follows the Person. Makes the Money Follows the Person Rebalancing Demonstration permanent.





The Arc®

New York
Regional Map



-  Western Finger Lakes Region
-  Central Region
-  Capital-Hudson Valley/Adirondack Region
-  Metro Region
-  No Chapter