



Alliance for the Betterment of
Citizens with Disabilities

Empowering People: Providers Shaping Policies

Assembly Human Services Committee

Testimony of Cathy Chin on A508

Respectfully Submitted on February 14, 2022

Good day, Chairperson Jimenez, Vice Chairperson Lampitt and members of the Assembly Human Services Committee. On behalf of ABCD, thank you for the opportunity to publicly express our gratitude to the bill's sponsor, Assemblyman Benson, and to express our support for an annual indexed rate increase which will cover all costs and services for community providers who serve people with developmental disabilities.

Not all, but most of our agencies are non-profits. Non-profits do not pay federal income, sales, and property taxes, but do pay employment taxes, benefits, wages and salaries, mortgages and rent, utilities, leases, vehicles, supplies, all manner of insurance, lawyers, accountants, auditors and must obey all federal, state, and local laws and regulations which pertain to businesses. They must hire and retain qualified staff and continue to provide quality best practices services and supports to individuals and their families.

Impact of Under Resourcing

Except for the minimum wage increases for DSPs and the significant increase to our day program rates beginning in October of 2021, thanks to Governor Murphy and the NJ Legislature, our system of care had not had an increase for overhead and operational costs in over a decade which left our programs particularly vulnerable during the pandemic requiring DHS to step in and provide emergency dollars to help cover staffing and overtime and ensure that our day program doors remain open at the conclusion of this crisis.

The pandemic also exposed the near impossibility of attracting and keeping physical, occupational and speech therapists in Early Intervention with the 2005 rate while competing with hospitals, nursing homes, assisted living facilities and 573 public school districts. Again, thanks to Governor Murphy and the Legislature this rate was increased in 2021.

Covid did not suddenly shine a light on unknown fragilities in our programs. We've all known and for a rather long time.

Impact of Targeted Funding

Targeted increases are effective but are not a long-term solution. For example, the DSP wage increases were sorely needed but also caused many of our professional staff, administrators, custodians, and other support staff to demand pay increases too. Prior to the inclusion of front-line supervisors in the DSP wage increase, many of them were demoting themselves to become DSPs so that they could collect overtime.

We agree with the reasoning for this bill, that it is incumbent upon State government to consider the full financial context in which the community provider operates to prevent crisis and interruption of services, enable leaders to focus on mission and outcome, and invest in the immediate and future health of the organization.

I respectfully request your consideration in clarifying and amending the legislation in the following ways:

- Most of our services are no longer under contract. Please consider clarifying the language to ensure that it includes providers who receive payment under the current FFS model in the Supports and Community Care Programs which would include residential services, day programs and services and for support coordination services.
- Please consider the inclusion of agencies which provide Early Intervention Services within DOH for infants and toddlers with developmental delays and disabilities.
- Would a Business Price Index be a more accurate measure of prices paid by our provider agencies than the Consumer Price Index which is used as a measure for adjusting payments to consumers?

Thank you for the opportunity to discuss why providers require resources and flexibility to run their agencies and programs effectively and efficiently



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Assembly Human Services Committee

Testimony of Cathy Chin on A1112

Respectfully Submitted on February 14, 2022

Good day, Chairperson Jimenez, Vice Chairperson Lampitt and members of the Assembly Human Services Committee. On behalf of ABCD, I would like to thank you for the opportunity to publicly thank the primary sponsors, Assemblywoman Chaparro and Assemblyman Benson, and to express our support of A1112 which requires the Department of Human Services and other appropriate State agencies to disseminate information on transportation options for persons with developmental disabilities.

The last legislative session saw two important transportation bills sponsored by Assemblyman Benson and Assemblywoman Murphy which were signed into law by the Governor:

- A2456 which confers automatic eligibility for and enrollment in motor bus and rail discounts for users of Access Link paratransit.
- A4208 creating the "Paratransit Services Improvement Act" which establishes a program to adopt paratransit best practices, requires greater coordination among paratransit service providers, and establishes regional paratransit coordinating councils.

Affordable, reliable, efficient, and user-friendly transportation will transform the lives of individuals with developmental disabilities, unlocking opportunities in education, employment, health care, housing, and community life. A significant next step in the struggle for civil rights and opportunity. As you know, the key to any successful program is giving potential beneficiaries enough information so that they can access it.

ABCD thanks you for working to ensure that individuals with developmental disabilities and their formal and informal supports are made aware of the transportation choices available to them to enable access to jobs and programs and a life in the community.

Thank you.



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Assembly Human Services Committee

Testimony of Cathy Chin on A1693

Respectfully Submitted on February 14, 2022

Good day, Chairperson Jimenez, Vice Chairperson Lampitt and members of the Assembly Human Services Committee. On behalf of ABCD, I would like to thank you for the opportunity to publicly thank the primary sponsors, Assemblywomen Quijano and Chaparro and Assemblyman Giblin, and to express our support of A1693 which creates a voluntary resume bank for individuals with a disability who wish to be appointed to a state board or commission.

New Jersey has well over a hundred state boards and commissions, yet many may not include people with disabilities. Many people with disabilities may incorrectly believe that one must have a certain expertise to be involved when in fact, in many instances, all that is needed is interest in the group's focus and in public service. The existence of the talent bank would encourage people with disabilities to consider volunteering for not just disability specific groups, but to be part of decision making in all areas to better represent not only the disability community but the community at large.

Thank you.



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Assembly Human Services Committee

Testimony of Cathy Chin on A2043

Respectfully Submitted on February 14, 2022

Good day, Chairperson Jimenez, Vice Chairperson Lampitt and members of the Assembly Human Services Committee. On behalf of ABCD, I would like to thank you for the opportunity to publicly thank the primary sponsors, Assemblyman Benson, and Assemblywoman McKnight and to express our support for A2043 "The New Jersey Disability Savings Act," which expands the NJ ABLE Program to incentivize qualified individuals and their families to save in ABLE Accounts for disability-related expenses without having to risk government benefits.

In this legislation, ABLE accounts would better correspond to and ensure a degree of equitability with NJBEST, NJ's 529 educational savings programs. The financial incentives in the bill are an additional attempt to attract qualified individuals and their families to participate in this program which I understand on a nationwide level needs more account holders to be sustainable.

Thank you.



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Senate Transportation Committee

March 7, 2022

Good day, Chairperson Diegnan and members of the Senate Transportation Committee. On behalf of ABCD thank you for the opportunity to publicly thank the bills' sponsor, Senator Diegnan, and voice our support of the following legislation under consideration today:

- S146 which requires certain transportation research to consider the needs of individuals with physical, sensory, intellectual, and developmental disabilities.
- S147 which requires DOT to implement a complete streets policy that considers persons with certain disabilities.
- S148 which requires NJT to expand or modify routes and hours of certain transportation services to solicit input from individuals diagnosed with autism.

Our thanks to Senator Diegnan for expanding S148 to include input solicited from individuals with not only autism but also developmental disabilities.

Affordable, reliable, efficient, and user-friendly transportation will transform the lives of individuals with developmental disabilities, unlocking opportunities in education, employment, health care, housing, and community life. A significant next step in the struggle for civil rights and opportunity.

Thank you.



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Assembly Women and Children Committee

Testimony on A4178

Respectfully Submitted on June 9, 2022

Good day, Chairperson Mosquera, Vice Chairperson McKnight and members of the Assembly Women and Children Committee. On behalf of ABCD, thank you for the opportunity to testify and publicly express our gratitude to the bill's sponsors, Assemblywomen Lopez, Speight, Carter, and Murphy. ABCD's Early Intervention Provider Association is comprised of 14 agencies which provide effective early support to over 60% of the children birth to three with developmental delays or disabilities enrolled in the early intervention system of services.

The current department which administers Early Intervention, the Department of Health, is very good at many things. For years they have worked hard to understand and effectively oversee our program, but the administration of direct human services has historically never been one of its strengths.

For Early Intervention, this cultural mismatch has and continues to have serious consequences for which the legislative and executive branches have often come to the rescue. We are grateful for this leadership and commitment, but in an aligned system, these crisis interventions would be rare, rather than the norm. Most importantly, how could these man-made crises not have impacted the infants, toddlers, and families we are charged to serve?

It is for these reasons, ABCD's Early Intervention Provider Association supports the creation of the Department of Early Childhood Development with its inclusion of the Early Intervention Service System.

It is our hope that this will be the last time the Legislature will have to come to our rescue. Thank you for your creativity, resolve, and leadership.



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Assembly Human Services Committee

Testimony on A3675

Respectfully Submitted, June 9, 2022

Good day, Chairperson Jimenez, and members of the Assembly Human Services Committee. Thank you for the opportunity to testify in support of A3675 and to publicly express our gratitude to the bill's sponsors, Assemblymen Verrelli, Mukherji and Benson.

The incidence and prevalence of mental health conditions for individuals with intellectual and developmental disabilities is typically two to three times that of the public.¹ This supports the estimate that between 30-57% of people with intellectual and developmental disabilities also experience mental health challenges.² Despite the frequency of individuals with intellectual and developmental disabilities having mental health conditions, this concurrence has often been misdiagnosed, understudied, and undertreated leading one industry expert to name this population as “the last and the least served.”³ Possible explanations for this include:

- For years the common thought was that you had to have a certain intelligence level to have a mental illness; that individuals with intellectual and developmental disabilities didn't have a high enough IQ to get depressed or to experience trauma.⁴
- Behavioral issues in people with intellectual disabilities were most often viewed as a function of their cognitive impairment rather than a symptom of an underlying mental health problem. It did not occur to clinicians that there might be an additional diagnosis, so they did not think to look for other explanations for behaviors.⁵
- A diagnosis of intellectual or developmental disability often overshadows the mental health issues so that the condition goes unrecognized.⁶

¹ Beasley, Joan B. *An Overview of START with Dr. Joan B. Beasley*, Institute on Disability/UCED, University of New Hampshire, 2016.) Webinar at www.centerforstartservices.org.

² Nicholson, D., Calhoun, A., McLaughlin, A., et al. *Care Experiences of Adults with Dual Diagnosis and the Family Caregivers*. (Global Qualities Nursing Research, 2017) *Jan-Dec: 4:2333393617721646*, 1-2.

³ Beasley, *Overview of START*.

⁴ Ibid.

⁵ Solomon, Andrew. *The Reckoning. The Father of Sandy Hook Killer Searches for Answers*. (The New Yorker Magazine, March 17, 2014) www.newyorker.com/magazine/2014/3/17/the-reckoning.

⁶ Evans, Ike. *Trauma Informed Care and Intellectual and Developmental Disabilities*. (Hogg Foundation for Mental Health, 2017). www.hogg.utexas.edu/trauma-and-idd?

- People with intellectual and developmental disabilities experience trauma, including abuse and neglect, at higher rates than the general population and are at increased risk of developing more severe post-traumatic stress symptoms than people without intellectual and developmental disabilities when exposed to the same traumatic event (Texas Health and Human Services). Trauma responses are often mistaken for willful noncompliance or lack of motivation.⁷
- Mental and substance use disorder treatment providers may underestimate the barriers of accessibility to their program or they may have specific exclusion criteria for some people with disabilities.⁸

“Immune,” unnoticed, overlooked, minimized, and excluded; whatever the reason(s) the personal, familial, and societal suffering and loss is immeasurable.

Recently, DDD approved an RFP which will create a total of 12 crisis stabilization beds in 3 Behavioral Health Homes across the state. To the extent that the intervention process differs from, and any incompatibilities can be cleared up with the START model outlined in A3675, it would be valuable to analyze and compare outcomes. In addition to creating more opportunities in the community for assessment, stabilization, and choice for our population, A3675 emphasizes prevention and respite. We support this bill which combined with actions undertaken by the Division may help create diverse models of care from which to choose and a broader service continuum to prevent emergent and acute care crises in our population.

⁷ *Mental and Substance Use Disorder Treatment for People with Physical and Cognitive Disabilities.* (SAMSA Advisory, 2019). HHS Publication No. PEP19-02-00-002.

⁸ *Ibid.*



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Promoting the Greater Good and Minimizing Harm

Add On to What is Working

Position on Senate Bill 957/Assembly Bill 3577

In the Fee for Service System, the State mandated that for Self-Directed Services (SDS) the self-directed employee (SDE) hourly rate be Reasonable and Customary. Passage of S957/A3577 would permit the SDE rate to surpass the current Reasonable and Customary rate by between 33 and 150% depending on the individual's acuity level. Though passage of this legislation may increase quality and stability of the SDS workforce, we believe it will do damage to the system as a whole; the superior policy is that which is currently promulgated by the State.

False Equivalency

Though Individual Supports is the same job and level of care for an individual whether provided by an agency or an SDS, the similarities end there; the provider agency is licensed while the individual/family home using SDS is unlicensed. The \$33 and \$53/hour paid to the licensed provider agency¹ covers labor costs and overhead in addition to the expenses incurred to observe hundreds of laws, regulations, and policies and comply with the States stringent quality requirements. The \$21-\$25/hour paid to the SDE employed by the individual/family covers labor costs. By and large, wage parity exists between agencies and SDS for this job category.

Regressive Policy

The proposed policy would incentivize an exodus of the Direct Support Professional workforce from licensed agencies to higher paying jobs in SDS. In addition to labor costs, licensed social service agencies provide their workforce with training, monitoring, supervision, benefits, career paths and complaint-recourse procedures, while transparent and accountable to the public.

- What is the long-term cost to the State when workers give up jobs with healthcare, retirement and other benefits for a job that solely pays more per hour?
- What is the long-term cost to the employee when they give up protections, support and a career path for a job that solely pays more per hour?
- By permitting one sector to pay one and a half times that of another, what is the long-term cost to a system that is already struggling to find enough front-line staff?

¹ \$33 and \$53/hour are the rates paid for Individual Supports services provided to individuals with out and with acuity levels, respectively.

- When policy is inadvertently structured to favor those in their own home, what is the long-term cost to the individuals who reside in licensed homes because they have neither the means, support, nor family to enable them to live and be cared for in their own home?

Under the current policy, the State meets its fiduciary duty to the taxpayer and its moral obligation to people with intellectual and developmental disabilities who rely on government for assistance. Though for some individuals this is not ideal, the existing approach promotes the greater good and minimizes harm.

Shared Interest.

We believe that the proponents of S957/A3577 have no intention to harm those who do not have the resources to live in their own home and are correct that we must continue to improve the quality and stability of our workforce. To achieve our shared goals, an annualized increase to counter the effects of rampant inflation must be across the board for all DDD supports and services and added on to a rate foundation which is largely working.

September 21, 2022



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Senate Health, Human Services and Senior Services Committee

Testimony of Cathy Chin on S2668

Respectfully Submitted on October 6, 2022

Good day, Chairperson Vitale Vice Chairperson Madden and members of the Senate Health, Human Services and Senior Services Committee. On behalf of ABCD, thank you for the opportunity to publicly express our gratitude to the bill's sponsors, Senators Greenstein, Vitale, and Gopal, and to express our support for an annualized inflationary increase for all DDD supports and services.

Due to the commitment, hard work, and talent of the Murphy Administration, the NJ Legislature and the Department of Human Services, the DSP wage remains above NJ's minimum wage¹ and the miscalculations of the past have been corrected - the Division of Developmental Disabilities day program and support coordination rates² have caught up with that of residential. We agree that now is the time to build on this success and make the most of a fortuitous moment in NJ politics.

A recurrent theme for social service agencies is the expectation that they will do more and more with less and less. But we jeopardize their existence and their ability to fulfil their mission when we fail to acknowledge that social service agencies are business organizations. And since they are rate takers and not rate makers, they are forced into a "make do and do without culture" - a culture that slowly starves them until the inconsistent intervention of government.

Meanwhile social service agencies are asked to take on an increasing share of society's most important and difficult work. In our case, further diversifying our world by supporting people with IDD to be free to fully live and participate in an integrated community, insuring that people on both sides of the disabled divide can thrive in the same place, and building a better system that stands up for human rights. Regrettably, agencies' financial reality undermines their ability to focus on achieving these results.

For this they need transformative investment in the form of rates which would continuously cover all costs, considering the full financial context in which the community provider operates. This transformative investment would help prevent crisis and interruption of services, enable leaders to focus on mission and outcomes, and invest in the immediate and future health of the organization.

I respectfully request your consideration in clarifying and amending the legislation in the following ways:

- Most of our services are no longer under contract. Please consider clarifying the language to ensure that it includes providers who receive payment under the current FFS model in the Supports and Community Care Programs which would include residential services, day programs and services and for support coordination services.

¹ Assuming the continued increase to DSP wages through January 2024.

² Assuming the annualization in the FY'24 Budget of the current Support Coordination rates.

- Please consider the inclusion of agencies which provide Early Intervention Services within DOH for infants and toddlers with developmental delays and disabilities.
- Would a Business Price Index be a more accurate measure of prices paid by our provider agencies than the Consumer Price Index which is used as a measure for adjusting payments to consumers?

The current political climate provides us with a window of opportunity to create lasting reform. Delay or inaction may mean a missed opportunity. "Politics is the art of the possible"³ but it always seems impossible until it is done.

³ Prince Otto von Bismarck, 1895



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Assembly Human Services Committee

Hearing on Employment Status of Persons with Intellectual and Developmental Disabilities

October 17, 2022

Good day, Chairperson Jimenez, and members of the Assembly Human Services Committee. Thank you for the opportunity to provide testimony regarding the status of employment for persons with intellectual and developmental disabilities.

When we ask participants in IDD day programs what their goals are, the most common reply is “a job.” People with disabilities want to work. Nevertheless, national surveys show 81% of adults with IDD do not have a paid job in the community and 46% of those individuals want one.¹ There has been tremendous progress to advance our goal of inclusion for individuals with IDD in the workplace. Due to the leadership of the NJ Legislature and NJBIA, many businesses and organizations are giving people with IDD the opportunity to make the same contributions and share in the same benefits as other employees. But as you know, more work needs to be done.

The passage of S3455/A5262 which will expand eligibility for the vital benefits of NJ Workability for those presently denied due to their income level, resources and age is huge; a significant step toward enabling people with disabilities to achieve their full professional potential. Thank you. We support the position of the self-advocates and families who oppose the imposition of a premium on this benefit and look forward to the findings of the recently convened stakeholder/DHS workgroup.

Start Early

Education from an early age for all system stake holders is critical. The people we serve, and their families should be getting the same message that we deliver to all youngsters. That eventually they will be entering the work force which will provide them with financial, social and health benefits including socializing with people based on commonalities rather than diagnosis.

- Families must be made aware of the advantages of work and the benefit protections in place, so that they do not summarily shut down the possibility for their son or daughter.

¹ The Inclusive Talent Pool: Employing People with Disabilities. Report of i4cp, 2019. www.i4cp.com

- DVRS job coaching should be available to individuals between 18-21 while in school.
- School and adult services must be aligned prior to graduation to prevent lapses in employment services and possible job loss.

Invest in High Quality Job Coaches

For the adult population, DHS and DOL have made great advances in the level of employment service and funding to provide people with training, accommodations, and supervision. The key to success is the expertise and dependability of the employment specialist and certified job coach who have developed working relationships with the client. The typical DVR set up works for many but because of the staffing crisis and low pay, the difficulty in training, recruiting, and retaining specialists and coaches is becoming an ever-growing roadblock.

Include Individuals with Complex Needs

For those with more complex needs, especially those entering the workforce for the first-time, additional time is needed for:

- Customized onsite coaching that is focused on social expectations and soft skills.
- Education and training of the individual's supervisors, managers, and co-workers.
- Education and support for the family who often have concerns and fears around taking their son or daughter out of a licensed human service program.

Overall, more SE service hours are necessary for individuals with complex needs, but their budget (tier) is often insufficient to cover the full cost for what is necessary. Providers must be compensated for success, and not penalized for taking the time to do it right.

It is for this reason that we thank Chairperson Jimenez for sponsoring A4539 which increases the hourly limit from 40 to 112 hours/calendar work week for personal care assistance services in NJ WorkAbility. Passage of this legislation would mean the difference between working and not working for many individuals with complex needs.

In Conclusion

Guardians, providers, support coordinators, and DDD must understand that something as important as employment requires no less of a commitment than it does for anyone else. Success will mean we must all put in the effort for the powerful rewards of freedom, pride and belonging that work can bring to the IDD population.



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Assembly Higher Education Committee

Testimony of Cathy Chin on A4613 and A4615

Respectfully Submitted on December 12, 2022

Good day, Chairperson Jasey, Vice Chairperson Carter, and members of the Assembly Higher Education Committee. On behalf of ABCD, thank you for the opportunity to publicly express our appreciation to the primary sponsor, Assemblyman Greenwald, and to voice our support of A4613 which extends eligibility and makes various other changes to the Primary Care Practitioner Loan Redemption Program and A4615 which requires the State to foster development and implementation of GME in behavioral health care.

New Jersey's person-centered system of care is working hard to provide mental health programs and services more adequately for the individuals they serve. Nevertheless, because of the prevalence of mental health conditions in individuals with intellectual and developmental disabilities, more assistance is required. Passage of A4613 and A4615 would expand the service continuum so that more individuals may have an opportunity to control and live their lives rather than have their lives controlled by mental illness.

Thank you.