Plan for Adequate Provider Supply for Services Provided Through the Innovations Waiver

Session Law 2021-180, Section 9D.12A

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Report to

Joint Legislative Oversight Committee on
Medicaid and NC Health Choice

by

North Carolina of Department of Health and Human Services

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I. Background

Session Law 2021-180 9D.12A **(see Appendix A)** directed the NC Department of Health and Human Services (DHHS) to report to the Joint Legislative Oversight Committee on Health and Human Services the plans for adding a minimum of 1,000 waiver slots in the 2023-2025 fiscal biennium and that contains recommendations for ensuring there would be adequate health care providers to support the needs of the additional beneficiaries.

North Carolina Medicaid oversees the 1915(c) NC Innovations Waiver and receives regular feedback on the waiver from beneficiaries, families, providers and Local Management Entities-Managed Care Organizations (LME-MCOs). The Innovations waiver was approved by CMS for five years effective July 1, 2019. The waiver is available statewide and is administered by the LME-MCOs.

The Innovations waiver provides community-based alternatives for individuals with Intellectual or Developmental Disabilities who meet the level of care for an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID). The waiver provides for a comprehensive continuum of care **(see Appendix C)** that includes habilitative and long-term support services that are provided within the home and community of enrolled beneficiaries.

There are 14,138 slots in the Innovations Waiver inclusive of both the additional 400 slots (March 1, 2022) and the additional 600 slots (July 1, 2022) that were made available pursuant to section 9D.12 of S.L. 2021-180. These slots are awarded on a first-come, first-served basis based on the date of application and the county of the beneficiary's administrative county of eligibility. Slots are equitably distributed among the subdivisions of the LME-MCO region based on population. As of February 28, 2023, there are17,008 people on the waiting list for the Innovations waiver. Of those individuals waiting for NC Innovations Waiver services, 39% are currently authorized for other services through Medicaid or State funds.

II. Plan for Adding Additional NC Innovations Waiver Slots in the 2023-2025 Fiscal Biennium

The current plan for adding 1000 Additional Waiver Slots between FY 2023-2025 includes:

1. Finalizing the process to determine how many individuals are receiving IDD services who are on the Registry of Unmet Needs (registry). These services include but are not limited to in lieu of state plan Medicaid services, state funded service, (b)(3)services and other 1915(c) waiver services.
2. Determine how many individuals will receive services under the new 1915(i) option services.
3. Learn from Innovations slot allocation process implemented in 3/1/22 and 7/1/22, which will allocate slots based on total Medicaid Population of a county and assign slots based on total population of a county when compared to the LME-MCO catchment area/BH IDD tailored plan region.
4. Determine total number of beneficiaries who are anticipated to transition from the Community Alternatives Program for Children (CAP-C) to the Innovations Waiver due to

aging out in FYs 2023, 2024, and 2025. Additional CAP-C Reserved Capacity slots will be held from the 1000 additional waiver slots to account for the anticipated CAP-C age outs in each of these years. There are currently 15 CAP-C Reserved Capacity Slots per Innovation Waiver Year (July through June).

5. Increase the Money Follows the Person Reserve Capacity Slots per Innovations Waiver Year (July through June) to 88 total slots to facilitate more transitions from institutional settings to the NC Innovation Waiver.
6. Increase the Emergency Reserve Capacity Slots per Innovations Waiver Year (July through June) to 97 total slots to support members that meet Emergency criteria as defined in the NC Innovations Waiver.
7. The State will propose an additional 1000 slots in the FY 2023-2024 budget. The State will also develop a lower tiered waiver to address individuals on the Registry of Unmet Needs.

III. Independence Waiver

The Department will be submitting a new 1915(c) "Independence Waiver" after thorough consideration of stakeholder feedback on the proposed model. It is important to note that the Independence Waiver is not a replacement for the Innovations Waiver and will serve as a complement to the Innovations Waiver, 1915(i) services, (b)(3) services (which are ending 6/30/24) and the LME-MCO developed in lieu of services. The Independence Waiver will be a 1915 (c) waiver with a $40,000 financial limit that will provide community-based alternatives for individuals with Intellectual and Developmental Disabilities who are at risk for placement in an ICF-IID, allowing more beneficiaries to receive support for community-based services and could decrease the waitlist for Innovations Waiver slots. Individuals who are on The Independence Waiver will have the ability to remain on the Innovations Waiver waitlist. The Independence Waiver will have the same rate assumptions of the NC Innovations Waiver with the goal to have an $18 Direct Care Worker wage. Of the 1,000 additional waiver slots in the 2024-2025 Fiscal Biennium, approximately 900 will be used to implement this waiver**.**

The key assumptions of the Independence Waiver are:

1. The Independence Waiver will only be available through the BH IDD tailored plan.
2. Access to the Independence Waiver will be on a "First Come, First Served" basis. Individuals who are currently on the Innovations Registry of Unmet Needs will maintain the time and date they were placed on the Registry of Unmet Needs.
3. Access to the Independence Waiver will be limited to beneficiaries who can be safely supported within the $40,000 yearly financial limit and with Supports Intensity Scale Levels of A, B or C. Beneficiaries will receive an Individual Budget Guideline to assist them with understanding the amount of support that people with their support needs typically require to be supported in the community.
4. The Independence Waiver will include the following service and supports:
    a. Assistive Technology – Allows for the purchase of equipment to help with tasks of daily life. This benefit will be limited to $10,000 over the 5-year life of the waiver and counts towards the $40,000 yearly financial limit.

   - b. Community Living and Supports – Supports beneficiaries to be independent in their homes and communities.
   - c. Community Networking – Supports beneficiaries with volunteering and participating in integrated classes.
   - d. Financial Support Services – Supports beneficiaries with filing claims and processing payroll for Self-Directed Services.
   - e. Remote Supports – Supports beneficiaries to be more independent by safely allowing for unstaffed time.
   - f. Respite – Provides family caregivers with relief from caregiver responsibilities.
   - g. Specialized Consultative Service – Provides training and technical assistance to support the individual.
   - h. Supported Employment – Supports beneficiaries with finding and keeping a competitive job in an integrated setting.
   - i. Supported Living – Supports beneficiaries with living in a home that they own or rent.
   - j. Supported Living Transition – Supports
   - k. Tailored Plan Care Management – Although not a waiver service, all members on the Independence Waiver will have access to Tailored Plan Care management.

5. All services and supports in the Independence Waiver will be "set to a pass through" if the total services and supports are within the beneficiary's Individual Budget Guideline. "Set to a pass through" means that if the request is within the beneficiaries Individual Budget Guideline, then the services will not require prior authorization from the BH IDD tailored plan. Beneficiaries and their teams will work with the BH IDD tailored plan Care Manager to develop their services and supports within the $40,000 Waiver Limit.

IV. Ensuring Adequate Providers

Recommendation to ensure adequate direct care work force are as follows:

1. North Carolina Medicaid implemented a rate increase as directed by S.L. 2021-180. The implementation will result in increased direct care worker wage increases of individuals on the Innovations Waiver. Although the rate increase has increased wages for Direct Support Professionals (DSP) in the Innovations waiver, it has not resulted in raising wages to a level that will stabilize this workforce. Competition from other health care sectors and non-health care sectors continue to make it difficult to recruit and retain workers. DHHS is evaluating the cost of increasing wages to be competitive in the market. We believe this is a multi-year plan that will include career stabilization as well as career pathways. DHHS will present this plan as part of a supplement to this report later this year. The plan will:

  - Increase rates for innovations waiver services by $3/ hour per hour in FY 2023-2024.
  - Increase in FY 2024-2025 consistent with the Innovations Wage and Rate Study to impact State Budget FY 2023–2025 conducted by Davidson, Holland, Whitesell & Co., PLLC and funded by the Developmental Disability Facilities Association (DDFA), the NC Provider Council and the NC DD Council (**see Appendix B**) with the goal of DSP salaries reaching $18/ hour in 2025.
  - Establish a DSP online certification program to begin in FY 2024-25. The program will be managed by NC Area Health Education Centers (AHEC). (The program may also refer to DSPs as Direct Support Works and use the acronym DSW; this reference to DSW will be inclusive of the IDD DSP workforce.
  - Establish a rate enhancement program based upon DSP certification program beginning in FY 2024-2025.
  - Create expectation that Innovations rates will increase based upon inflation beginning in FY 2025-2026.
2. Reduce Utilization Review Administration and provider burden by removing prior authorization requirements.
3. Adoption of the Remote Supports service to allow individuals to safely spend time without 1:1 support as appropriate. Remote Supports is a service that allows beneficiaries to use technology to monitor their health and safety during times without direct care staff. This change will help reduce the number of DSPs needed.
4. Streamlining the Self-Directed Options to allow beneficiaries who self-direct to pay increased wages and have more ownership of their services.
    a. Innovations Waiver services are most commonly provided through a Provider Agency. Self-Directed Options allow the member or legally responsible person the opportunity to direct the member’s services. This often allows the member or legally responsible person to pay higher wages as there is less administrative cost. Additionally, the Self-Directed Options also allows people to pay bonus out of the fund balance that is generated through service billing. Finally, it allows for the employment of relatives as Direct Support Professionals.
    b. The NC Innovations Waiver limits the type of services that relatives, who live in the same home as the member can, provide. Through COVID-19 public health emergency flexibilities, relatives who live in the same home as the member can provide a broader set of services to the member. DHHS is working to allow relatives to provide additional services on a permanent basis.

V. Next Steps

- DHHS will continue its evaluation and present an updated report by December 1, 2023.
- DHHS will begin publishing the rate of services provided vs. services authorized beginning July 1, 2023.
- DHHS will publish quarterly the percentage of individuals receiving services who are on the registry by Tailored Plan beginning July 1, 2023 (Currently 39% of individuals on the registry are receiving some type of service).
- DHHS will work with community stakeholders to gain feedback on both the Independence Waiver and the increase in the NC Innovations reserved capacity for Emergencies, Money Follows the Person and CAP-C age out slots.
- DHHS will incorporate feedback and submit the Independence Waiver to the Centers of Medicare & Medicaid Services.
- DHHS will amend the Innovations Waiver to increase the reserved capacity associated with for Emergencies, Money Follows the Person and CAP-C Age Outs.
- DHHS will work with the Tailored Plans to perform Supports Intensity Scale Assessments on a predetermined number of individuals on the Registry of Unmet Needs to determine beneficiaries who may benefit from the Independence Waiver.

Appendix A: Session Law 2018-81, Section 9D.12A

S.L. 2021-180 9D.12A PLAN FOR ADEQUATE PROVIDER SUPPLY FOR SERVICES PROVIDED THROUGH THE INNOVATIONS WAIVER

SECTION 9D.12A. The Department of Health and Human Services, Division of Health Benefits (DHB), shall begin to plan for additional North Carolina Innovations waiver slots that could be added in the future. No later than March 1, 2022, DHB shall submit a report to the Joint Legislative Oversight Committee on Medicaid and NC Health Choice that outlines the plans for adding a minimum of 1,000 waiver slots in the 2023-2025 fiscal biennium and that contains recommendations for ensuring that there would be adequate health care providers to support the needs of the additional individuals served under the waiver should the number of slots be increased in the future.

Appendix B: Innovations Wage and Rate Study to impact State Budget FY 2023 – 2025

Innovations Wage and Rate Study to impact State Budget FY 2023 – 2025

- Herb Whitesell, CPA is the Managing Partner of Davidson, Holland, Whitesell & Co., PLLC. North Carolina IDD is DHW's largest industry focus in our 45-person CPA firm with offices in Hickory, NC and Morganton, NC. We have served NC IDD Providers since 1990 and LME/MCOs since 2012.

- DHW, CPAs were commissioned in the fall of 2022 by the NCCDD, the NC Providers Council "NCPC", and the Developmentally Disabled Facilities Association "DDFA" to perform a study of Innovations caregiver wages and related Innovations reimbursement rates.

- The Goal - To determine the estimated amount of Medicaid funding required to move the average hourly rate of Direct Care Workers "DCW" to $18.00 per hour, as well as the additional labor "burden" necessary for employer payroll taxes and employer paid employee benefits.

- Surveys of a sample of IDD Providers rendered a pre-Covid average hourly rate of $11.50/hour. Then we pivoted to determining the amount of annual recurring funds needed to add $6.50, or a goal of $18.00.

- Initially the study was done independent of NC Division of Health Benefits. We later moved to a cooperative effort, using more data available from NC DHB and DHB's actuarial consultants – Mercer.

- As of this writing, our projected overall spend necessary to fund the $6.50 hourly wage increase + labor burden for 14,138 Innovations slots is approximately $245M. The state portion of that, assuming an estimated 67% FMAP, is $80M annually recurring.

- Since more Innovations slots are being considered, the incremental spend to help new workers also reach $18.00 (not $11.50 - assuming the funding for $11.50 would already be tied to the increased slots budget), would be $22.5K Total / $7.5K State **per added slot**.

Appendix C: Stories from People Served by the Innovations Waiver

These stories were compiled by the North Carolina Direct Support Professional Workgroup. The North Carolina Direct Support Professional Workgroup is an advocacy group working on the crisis in DSP staffing. It is comprised of people with disabilities, their friends and family members, and supported by IDD professionals.

DSPs: Direct Support Professionals are paraprofessional staff that provide important services and supports for people with disabilities. They work in the homes of families of a person with a disability, group homes, and almost anywhere in the community. They teach new skills to people with disabilities and help them perform functions that they cannot do for themselves. Nearly every single service offered in the state of North Carolina for people with intellectual and developmental disabilities (IDD) depends on DSPs.

The following are stories from people served by the Innovations waiver, their friends and family, one of their providers, and a DSP. These stories illustrate how important DSPs are and the hardships people face because of the shortfall in workers available to be employed as DSPs.

Story #1: A Friend's Story

My friend recently lost his mom, who was a very important part of his life. She died last year. He lives independently, however depends on the support of another person to get dressed, to bathe, and for most other regular activities of daily life. This is because he has limited use of his limbs and needs to use a wheelchair. He also has some difficulty with speech.

My friend only has one Direct Support Professional (DSP) because of the DSP crisis. He has been advertising and working with his provider to look for another DSP but has not been able to find one. This is a crisis for him just like it is for so many people with developmental disabilities across the state.

Putting so much demand on one DSP leaves very little time for that person to take care of his own personal needs. And God forbid that anything detrimental happens to his one DSP! His only other supports are his grandparents. They are getting older in age and live almost an hour away.

We all have shortcomings; my friends are just more visible than mine. Regardless of his disabilities, my friend is a highly accomplished individual and an active part of his community. He works as a Community Inclusion Specialist at Solutions for Independence. He is Chair of the North Carolina Council on Developmental Disabilities. He previously chaired two other disability rights organizations.

If my friend does not have the support he needs from a DSP, he doesn't know what will happen to him. He has accomplished so much! But it is all at risk without the support that he needs.

Story #2: A Young Man's Story

Having a DSP has been extremely helpful in my everyday life. I have a lot of need for physical help to get through my day. Ever since I had a DSP to help me, my days have been much easier not only for me, but for my mother. She has been a big supporter in my life but deserves a break. That is where the DSPs come into play.

A DSP helps me get up in the morning. They help me go through my day even if that means taking me to the store, going through my goals, taking me to the bathroom, giving me a shower, and doing my chores because I cannot do these things on my own. When they help me with my goals, this means my DSPs help me have experiences that I could not have on my own. They help me learn to be more independent in the community. They have taken me to the park, museums, movies, and bowling. I enjoy the time that they are with me. This makes me feel like I am doing things on my own, which makes me happy.

When my DSPs are with me, they treat me like their family or a friend. Not like someone who is paid to come and take care of me. This helps me build a better perspective as far as my self- esteem goes. When a DSP is not available to help me, things seem to be harder due to my special needs. I keep asking my mom what I am going to do if an emergency comes up, even though I know that my mom will be here to help me. I want to be as independent as I possibly can, and I rely on the DSPs a lot. They make my day! If there is one day that a DSP cannot show up due to an emergency or being sick, then I start to freak out because I feel like nothing is going to get done. I get upset. DSPs are essential to my life and happiness. Having DSPs here brightens my day and allows me to open up and enjoy my life.

Story #3: A Mother-Daughter Story

Mother: My 26-year-old daughter is an amazing person! She has a disability, but she is a college graduate and employed. She lives independently with roommates. However, because of her disability she cannot feed herself or get out of bed without the help of DSPs. She relies on a number of DSPs helping her throughout the day but handles her own overnight needs. Her Innovations plan calls for her to have 84 hours of DSP support each week. However, this amount of support is not consistently available.

The current lack of DSPs means that I have frequently been called upon to provide her care; I have provided more than 142 hours so far since January. I am happy to support my daughter, but I know she wants to live independently. My main concern is, “what will happen when I am no longer able or around to provide her care?”

The Innovations Waiver is designed to make it possible for persons with disabilities to live in their own homes instead of in a facility. The Waiver is supposed to help people with disabilities achieve their maximum level of independence. If the DSP crisis isn’t fixed, my daughter will not be able to continue to live independently. We will have to consider moving her into either a group home or another residential facility.

It breaks my heart to think that all that she has worked so hard to achieve could be lost because of the lack of DSP staff!

Daughter: I live in my own home and have a job. I rely on DSPs to help me get out of bed, bathe, eat, etc. According to my Innovations Plan, I am supposed to have DSP support 84 hours per week. These hours are divided across three people, however there are only two people helping me right now, and they were just hired recently. When no DSP shows up in the morning, I have to wait in bed until my mom can arrive to take care of me. She lives 60 miles away. There are several shifts during the week that are vacant and are staffed with fill-ins. If my provider cannot find staff to fill in, my mom has to come help me. Mom is starting to talk with me about what happens when she is no longer able to help me or after she is gone.

I am only 26 and I am very proud of my independence! But I worry about keeping it. How can I live in my own home and keep a job if I can't get out of bed reliably in the mornings?

Story #4: Story of Two Parents Doing their Best

Our son has very complex needs. His Innovations Plan calls for him to have 84 hours of support each week. This means that he depends on us to take care of him the other 84 hours of the week. This support through the Innovations Waiver is supposed to be provided by specially trained and paid DSPs that come to our home. However, the DSPs are not available to cover all of the 84 hours. So, we serve as back-up when regular staff are not available.

Finding qualified staff to work as DSPs has never been easy. The hours of service that our son needs have never been fully covered by DSPs during the entire 21 years that he has been enrolled in the Innovations Waiver. This has become increasingly worse over the past 7 years. We recruited the DSP that is currently working with him. The Provider had no candidates for almost a year.

The DSP job is challenging. Salaries are low and the person currently serving as his DSP wants to work a minimum of 48 hours per week to earn enough money to make ends meet. However, the Provider that employs him does not allow staff to work more than 40 hours per week. The day program, the in-home, and the respite providers are different companies. This means that the DSPs cannot cover for one another. During a recent emergency, no staff were available to provide support, not even the supervisor.

Since there are no back up staff, my husband and I serve as the only available back up staff when the DSP is sick or on vacation. Both of us are paid under the Relative as Provider provision of the Innovations Waiver. Only one of us can work a regular job outside of our home because of the lack of consistency in DSP availability. This means that our family income is much less than it would be if both of us could work.

Our son receives far less support than called for in his Innovations Plan; and the inconsistency of services is not good for him as well as stressful and disruptive to our life as a family. We gladly provide care for him for the 84 hours per week that is not covered by his Innovations Plan. However, the lack of DSP staffing means that more of the time we spend with him is spent carrying out formal goals instead of just being his parents and supporting his happiness.

Story #5: A Father's Story

Our son is 31 years old, the middle of 3 brothers. He was born with Down Syndrome. He brought great joy into our lives and is a valued member of our family. He got an Innovation Waiver slot at age 9. When he was young, having support services provided by a DSP gave me the ability to pay attention to his brothers and spend time with them. It also gave me the ability to do all the things every family does: help with homework, take kids to scouts, baseball, band practice, cook, clean, etc.

The DSP becomes a part of your regular day or week. Relationships and bonds form with DSPs. These relationships are important when a person is spending so much time in your home. Unfortunately, these bonds are broken quite frequently due to the DSP moving on to other jobs.

At age 31, our son is an adult with a life independent of our family, just like his brothers. He is very stable on his medication regimen and has been very active in his day program. He has lived independent of us for the last few years through the Supported Living Level 2 Service of the Innovations Waiver. He does enjoy living away from his mom and dad, just like any other 31-year-old!

However, barriers remain. Our son lives in an apartment that requires parking stickers to park. His DSPs are unable to have a parking sticker because they are not tenants. The saga continues of always pushing hard to get what he needs and what he should rightfully have to live his life.

Our goal is always to develop a strong, consistent team to enable him to be as independent as possible. However, at the present time, a consistent team is not in place due to the shortage of DSPs. This means he has been spending more time at home with us. Having DSPs provide the support called for in his Innovations Plan is essential for our son's independence and self-esteem. Our family has worked hard to help him achieve his independence and we are so proud of him! Please help us keep our DSPs!

Story #6: A Story of Determination

Our son is 31 years old and has an intellectual and developmental disability (I/DD). He is one of the fortunate adults in North Carolina to have the Innovations Waiver. He is also one of only 83 adults in the state with a developmental disability using the Medicaid Service of Supported Living, Level Three, allowing him the opportunity to live in a home of his own with one-to-one support. This means that he has 168 hours per week of DSP support assisting him in his home and community.

Since moving out of congregate care and into his own home, he is living a life of dignity and purpose. After being in institutional care, he has spent over four years living in his own home. During this time, his emotional well-being, interpersonal relations, self-determination, social inclusion, and physical and psychological well-being have increased exponentially.

However, the move to full inclusion in the community for our son, while now wildly successful, has not been easy. In fact, it has been the most challenging four years for his family in our son's over 31 years. Over the entire four years it has existed, our son's home has never been fully staffed. Because we are committed to his happiness and success, and even though my husband and I work full time, we have provided over 2,500 hours of unpaid coverage for DSP vacancies. We are now paid by his provider when we fill in for vacancies in DSP staff.

However, filling in for DSP vacancies means that we have had to use our paid time off and vacation time to provide this support. We have left work meetings, doctor appointments, cancelled occasional weekends out of town, and left friends' homes in the middle of dinner to cover open shifts. This means that a lot of the time we spend with our son is spent carrying out his goals; something essential for him to maintain what he has accomplished. We would much prefer our time with him to be family time, so we could enjoy the person he has become!

How we treat our most vulnerable citizens speaks volumes. Unless or until our General Assembly prioritizes North Carolinians with developmental disabilities and addresses the vacancy rates and critical shortage of direct support professionals by providing funds to increase rates of pay to a competitive level, people with I/DD and their families will continue to suffer collateral damage in their lives.

Story #7: A Mother's Story about Her Son

DSPs are an important presence in our lives. They work in our homes, provide essential support, intimate care, and become part of our family. My son has physical disabilities and needs assistance with many activities of daily living. Thankfully he is enrolled in the Innovations Waiver. He is now 33 and is an incredible young man!

I believe a special DSP was sent to assist our family after my husband passed and when my son was just 16 years old. This special DSP had been a medic in the Navy and was in his 50's when he came into our lives. For fifteen years, he came every morning Monday-Friday at 7 am for one hour to get my son up, dressed, address his hygiene needs and then help him with breakfast. This man was a godsend, a close friend, and a surrogate father to my son during a critical period when he was becoming an adult. He was committed, driving over 20 miles each way and rarely missed a morning. This special DSP has always wanted to listen, care and help people. The money was not the reason he came.

They say God sends to us what we need most, and this special DSP was that. I loved to hear the laughter of my son and his special DSP and how they started their mornings together. We always knew that this special DSP and his wife wanted to move to Florida when they could. His wife, who is a Pastor, was recently offered a church there. To tell you that saying goodbye was a sad time is an understatement!

There are other DSPs out there like him, but they have young families to care for as well. We have a second DSP who has been with us for going on 10 years. He has 2 children, and his family receives public assistance. We know we are on borrowed time because of the low pay; and if he leaves, there goes 48 hours of our coverage. A third DSP, who had been with us long term as well, left to work at a hospital. He went from making $12 an hour as a DSP, to $36 an hour working as a hospital orderly. He loved working with my son, but he had to change jobs to support his family; he had no choice.

This is reality in our world. Something has to change!

Story #8: A Mother's Story about Her Daughter

I write to you today to share an example of the very real and ongoing crisis in our state with the DSP workforce that impacts our most vulnerable citizens.

My 30-year-old daughter is diagnosed with severe intellectual disabilities and chronic and difficult to manage medical conditions, requiring nursing care and 24-hour monitoring. She is a sweetheart, fun to be with, and easy to support. After she experienced a medical crisis resulting in a permanent health condition six years ago, she was discharged from a group home because they could no longer meet her medical needs. We were fortunate that she was enrolled in the Innovations Waiver, and care was transferred to my home.

My experiences as a social worker and working in the LME/MCO arena for the last decade have afforded me a stark advantage over other parents in navigating the NC Innovations Waiver. Despite this advantage, I struggled. I persistently searched for staff only to find again and again that they would abandon the position for higher paying employment---a vicious cycle and detrimental to my daughter's habilitative and medical well-being.

Working with two and even three provider agencies still did not yield the staffing coverage my daughter needed, and it has been impossible to find staff at night to relieve me and provide the care she needs during the night. Her father and I are divorced but have worked together to take care of our special daughter. She stays with each of us for two nights at a time. We must always get up for several hours during the night to provide the medical care that she must have. We both work full time and the physical strain we experienced from six years of interrupted sleep has been debilitating.

Caring for people with disabilities in the community is a cost-effective solution for North Carolina. However, DSPs that provide services in the state facilities (institutions) make a minimum of $15 per hour, a salary that community DSPs can only dream of. Providers of Innovations Waiver services cannot compete with retail and fast-food businesses in the community that offer starting salaries of $18 per hour and higher.

The Innovations Waiver offers community services as an alternative to facility based (institutional) services. This promise of community living, as an alternative to institutional care, is a promise broken, and an illusion for many North Carolina families!

Story # 9: Older Parents Worried about their Son's Future:

Our 46-year-old son has autism and I/DD. He needs 24/7 support because he requires full care, doesn't sleep at night, and has toileting issues. He lives in his own home through the Innovations Waiver Supported Living Program. **Our DSPs are the linchpins which keep North Carolina's Supported Living system running.** Our DSPs are wonderful caregivers who make all the difference in our son's life.

Our DSPs are paid very low wages and have almost no benefits. They either have 2-3 jobs, or they work 90 hours a week just to make ends meet. When their cars break down, they need to care for themselves or their children, they have no sick days or paid vacation. That is when they have to ask us to help. The provider has no substitutes or back-up staff available for emergencies.

We parents are nearly 80 years old. Every day we fear our DSPs will quit and our son will be forced back into an institution!

Story # 10 : A Provider's Story

Our provider organization is very grateful for the concern of the North Carolina General Assembly for people with disabilities and the crisis in staffing that is plaguing our industry. We know that any action taken by the General Assembly is an important step in addressing a very complex problem that has no simple solution. Recent legislation designating funds for salary increases, while not resolving the problem, is sincerely appreciated!

We are a not-for-profit, state-wide provider of services for people with IDD, as well as people with Mental Health and Substance Use conditions. There are three main funding streams for services for people with IDD. These are Innovations Waiver Funding, state funding, and other Medicaid Funding. The programs we operate are supported by blended funding from these three funding sources.

Recruitment and Turnover: Despite all our recruitment efforts, the turnover rate for DSP employees increased from 23% in 2020 to 41% in 2021.
There is an average of 125 positions that are continuously vacant in our Innovations programs.
Despite continuous recruitment, we have not been able to reduce the turnover and vacancy rate. Some positions have been vacant since 2019. We have worked hard to retain employees, offering more time off, bonuses, extra training for managers in retention strategies, movie tickets and other perks. Hiring strategies have also been reviewed, now offering sign on bonuses, searching linked-in profiles, providing hiring ads in non-traditional places, and loosening hiring qualifications.
Throughout the state, providers compete with the Retail and Fast-Food Industry for employees that can be trained to become DSPs. Retail and Fast-Food businesses are advertising starting rates of pay between $15 and $22 per hour, with other benefits such as sign on bonuses and paying college tuition.

Impact of the Shortfall in DSP employees: Staff burn-out from covering for vacant positions is the highest it has ever been. Staff burn-out and fatigue impacts the quality-of-service delivery in many ways. For people with disabilities, continuously changing DSP staff involved in their care is disruptive; it affects their sense of security and overall well-being.

Revenue Increase: Medicaid rates, including Innovations rates were increased by $2.16 per hour based on last year's legislation. We used the entire amount to increase staff salaries—no overhead. This allowed us to increase staff salaries to $13 per hour.

An additional challenge: An additional challenge we face (as well as many others) is how to fairly compensate all employees doing the same work. Clearly there is *no basis* to pay employees differently according to funding source.

This is especially problematic because DSP employees paid from different funding sources, are working side by side in the same settings. Individuals served by the Innovations Waiver are not segregated from other people who are funded by the state and other Medicaid programs. Some Innovations recipients receive both Innovations and state funded services. We have very few staff that are paid entirely from Innovations Waiver funding. We had to increase the salaries for all of our DSPs, even employees primarily funded by state dollars. (State funding for services has not been increased in more than twenty years.)

Providers of services for people with intellectual and developmental disabilities do not have significant financial reserves. *There is very little, if any profit margin* in state and Medicaid funded services, and even large providers operate with constant worry about bringing in sufficient revenue to cover their costs.

Story #11: A DSP's Story

I have been a DSP going on two years now. My main responsibilities include helping disabled people become more independent, and with their overall living needs. My outlook as a DSP is that the job can be harder than one can imagine. What I mean by this is that some individuals are independent whereas others need a lot of care. This means my work is very different depending on the client that I work with. I am required to transport clients in my car because many of their goals are about involving them in the community.

My pay, no matter what, is the same for each client. I make $12 an hour, which if you consider all the driving that I have to do and gas prices, comes out to me hardly making that. I did an experiment for my round trip of working and I drive roughly around 100 miles a day. My employer has only offered to pay me $7.25 an hour for my drive time. As far as benefits go, my provider offers health insurance; but at $300 per week, if I chose that plan I would be almost working for free! Without an increase in pay, providers will not be able to keep anyone because people can go to Walmart and make a lot more money.

Some clients have behavior problems and I have not had much training on what to do when this happens. One client threw a cane at me which cracked me in my spine. This caused a great deal of pain in my back. My provider paid for me to go to the doctor, but I still experienced a lot of pain, and this made my life very hard. Providers should pay more when people are working with difficult clients, as well as provide training in a better way to handle them. I have worked in the healthcare field for quite some time, and so in many cases I know what to do. However, other staff have not had this experience. The training needs to be better than just sticking someone in the field and expecting them to know what to do.

If something is not done to compensate people better for their hard work, provide affordable benefits and pay for travel expenses, providers will not be able to keep any staff. What I would like to see change is an increase in pay, better benefits, and better training. I like working in healthcare and with people that need my help. My work with my clients is good. They all greet me, and we accomplish a lot throughout the day. But I feel that the system is failing them because the job requires a lot of skills, and the pay is so low. Because of all these challenges, I feel concerned because some families have a tough time getting people to help them.