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FINAL REPORT OF THE SENATE STUDY COMMITTEE ON PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND WAIVER PLAN ACCESS (SR 770)

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Prepared by the Senate Research Office, 2022

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STUDY COMMITTEE CREATION, FOCUS, AND DUTIES

The Senate on People with Intellectual and Developmental Disabilities and Waiver Plan Access Study Committee was created by Senate Resolution 770, authored by Senator Sally Harrell of the 40th, during the 2022 Legislative Session of the Georgia General Assembly.[1] The Study Committee was tasked with looking at the home and community support structures that are provided to individuals with intellectual and developmental disabilities (IDD) and recommending a plan for how to adequately serve individuals with IDD.

Senator John Albers of the 56th and Senator Sally Harrell of the 40th served as bipartisan Co-Chairs of the Study Committee. The other Senate members were Senator Dean Burke of the 11th, Senator Donzella James of the 35th, and Senator Marty Harbin of the 16th. Additional members appointed to the Study Committee included Brian Dowd representing the Department of Community Health (DCH), Ashleigh Caseman representing the Department of Behavioral Health and Developmental Disabilities (DBHDD), and D'Arcy Robb representing the Georgia Council on Developmental Disabilities (GCDD).

The following legislative staff members were assigned to the Study Committee: Rachel Moore, Senate Press Office; Josselyn Hill, Senate Research Office (SRO); Ali Farmer, Office of Senator John Albers; Keridan Ogletree, Office of Senator Sally Harrell; Kaitlin Little, Senate Budget and Evaluation Office; and Betsy Howerton, Office of Legislative Counsel.

The Study Committee held meetings on:

- July 26, 2022 (State Capitol);
- August 24, 2022 (State Capitol);
- September 21, 2022 (Rome, GA);
- October 19, 2022 (Tifton, GA);
- November 16, 2022 (State Capitol); and
- December 14, 2022 (State Capitol).

[1] S.R. 770, 157th Gen. Assemb., Reg. Sess. (Ga. 2022), https://www.legis.ga.gov/legislation/63002.

BACKGROUND, SUMMARY OF TESTIMONY, AND DISCUSSION

Meeting One – July 26, 2022 (State Capitol)

Senator Harrell and Senator Albers opened the Study Committee meeting explaining that this meeting was serving to provide background information regarding IDD services. Senator Harrell indicated that concerns have been voiced by groups, parents, individuals, and organizations in regard to whether the IDD community is being properly cared for and provided with the services they need within the community. Senator Albers explained that the Georgia General Assembly has taken some significant steps over the years to help individuals with IDD by passing legislation such as Ava's law. Senator James echoed similar sentiments regarding the importance of this Study Committee.

Senate Research Office Presentation (SRO)

SRO explained that a 2022 study conducted by Policygenius ranked Georgia as the 49th state to live in as an individual with an IDD.[2] According to the study, the top five states are Massachusetts, Pennsylvania, Vermont, North Dakota, and Maryland. The bottom five states are: Mississippi, Alabama, Georgia, Arizona, and North Carolina.

The presentation covered the four major categories that the survey analyzed: economic data, affordability, livability, and healthcare and insurance. Based on Georgia's economic data[3], Georgia is ranked 43rd for residents who have IDD and are in the labor force. Their median earning is $22,895.00, their poverty rate is 21.9%, and their unemployment rate is 15.9%. Georgia's ranking on affordability[4] is the highest ranking it received in all four categories with a rank of 34th. In Georgia, a livable wage (a wage that allows residents to meet minimum standards of living within the state) is $12.46 per hour, the monthly housing cost is $972.00, the average monthly Supplemental Nutrition Assistance Program (SNAP) benefit is $126.00, and the percent of disabled residents in public housing is 16%. Livability[5] measures how easy it is for a resident with IDD to get around, Georgia ranks 38th in this category. Georgia's walkability score is 26/100, the number of ADA-accessible transit stations is 70/100, and the average commute is28 minutes. The state of healthcare and

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[2] SRO further explained that this index compares more than two dozen factors grouped into four categories which include economic data, affordability, livability, and the state of healthcare and insurance. Each of the four categories received their own ranking and the final rankings were determined using an average of the four.

[3] The economic data looked at six metrics related to the financial situation of residents with disabilities. These six metrics are: 1) median earnings: 2) labor force participation; 3) unemployment rate; 4) poverty rate; 5) ticket to work offices' and 6) ticket to work tickets. The Ticket to Work program is a federal program that helps you to find and apply for jobs that already exist in the marketplace.

[4] Affordability is measured using six metrics which are: 1) livable wage; 2) monthly housing costs; 3) housing costs as a percent of income; 4) percent of residents with IDD in public housing; 5) percent of households receiving SNAP benefits; and 6) average SNAP benefit per person.

[5] Livability is measured using seven metrics which are: 1) walk score; 2) transit score; 3) ADA-accessible transit stations; 4) percent of population using public transportation; 5) average commute time to work in minutes; 6) population of residents with IDD; and 7) percent of state residents that have a disability.

insurance[6] is the final category with Georgia ranking 43rd. The percent of disabled residents with health insurance is 89%, the average Medicare bill is $64.00, and the average Social Security Disability Insurance (SSDI) benefit is $1,198.00.

SRO also explained that according to the 2022 Case for Inclusion study conducted by the United Cerebral Palsy and ANCOR Foundations, Georgia has 20,000 plus people waiting for Home and Community Based Services (HCBS). SRO further indicated that this number is unlikely to be representative of the actual number of individuals on the waitlist because there are definitional limitations and comparisons that skew the data sets when trying to compare all 50 states with regard to how they measure those who are on waitlists. DBHDD was able to provide an accurate number of the individuals on the waiting list for COMP and NOW programs. Currently there are 7,155 individuals on the waitlist for COMP and NOW services. DBHDD further explained that the 20,000 plus cited by the Case for Inclusion probably accounted for all the waiver programs not just those focused on individuals with IDD along with those who have not applied or been deemed eligible for waiver services.

In Georgia, IDD services are funded via state dollars and two types of Medicaid waivers, NOW and COMP. The NOW waiver offers services and support to individuals to enable them to remain living in their own family home and participate or live independently in the community. The COMP waiver provides services and support to individuals with more intensive needs and focuses on providing residential care for individuals with IDD

In 2022, the following services are funded through NOW include but are not limited to: adult occupational therapy; adult physical therapy; adult speech and language therapy; behavioral support services; community access; community living supports; in home and out of home respite; environmental accessibility adaptation; interpreter services; individual directed goods and services; financial support services; prevocational services; specialized medical equipment and supplies; support coordination; supported employment; transportation; vehicle adaptation; skilled nursing services; and nutrition services.

In 2021, the following services were funded through COMP include but are not limited to: adult occupational therapy; adult physical therapy; adult speech and language therapy; behavioral support services; community access; community living supports; community residential alternative; in home and out of home respite; environmental accessibility adaptation; additional staffing; prevocational services; specialized medical equipment and supplies; intensive support coordination and support coordination; supported employment; transportation; vehicle adaptation; skilled nursing services; nutrition services; interpreter services; individual directed goods and services; and financial support services.

There has been an effort to increase telehealth access for COMP and NOW waiver programs in the following service areas: adult speech and language therapy, adult occupational therapy, adult physical therapy, adult nutrition services, behavior support services, interpreter services, and supported employment services.

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[6] The state of healthcare and insurance has seven metrics which are: 1) accredited health departments per capita; 2) percent of resident with IDD that have health insurance; 3) Medicare enrollees; 4) Medicare providers per capita; 5) average Medicare bill per person; 6) average the Old-Age, Survivors, and Disability Insurance (OASDI) benefit; and 7) average SSDI benefit.

Department of Community Health Presentation

DCH provided a brief overview of their role when it comes to the waivers. DCH explained their role as the single state Medicaid agency which means they are tasked with negotiating with the Centers for Medicare and Medicaid Service (CMS) regarding HCBS waivers. DCH indicated that there are different kinds of waivers in Medicaid. The 1915C waivers are the HCBS waiver programs. DCH explained that the state Medicaid program is like an insurance program. A comparable example would be Blue Cross and Blue Shield or Kaiser. At the beginning of each year, they send their enrollee a booklet informing them of the eligible coverage through their insurance company. Similarly, the state Medicaid plan shows services in Medicaid that an individual is eligible for and any limitation on such services. However, state Medicaid provides additional services for those individuals who meet medical necessity requirements. For these particular services, the state provides special programs called waivers.

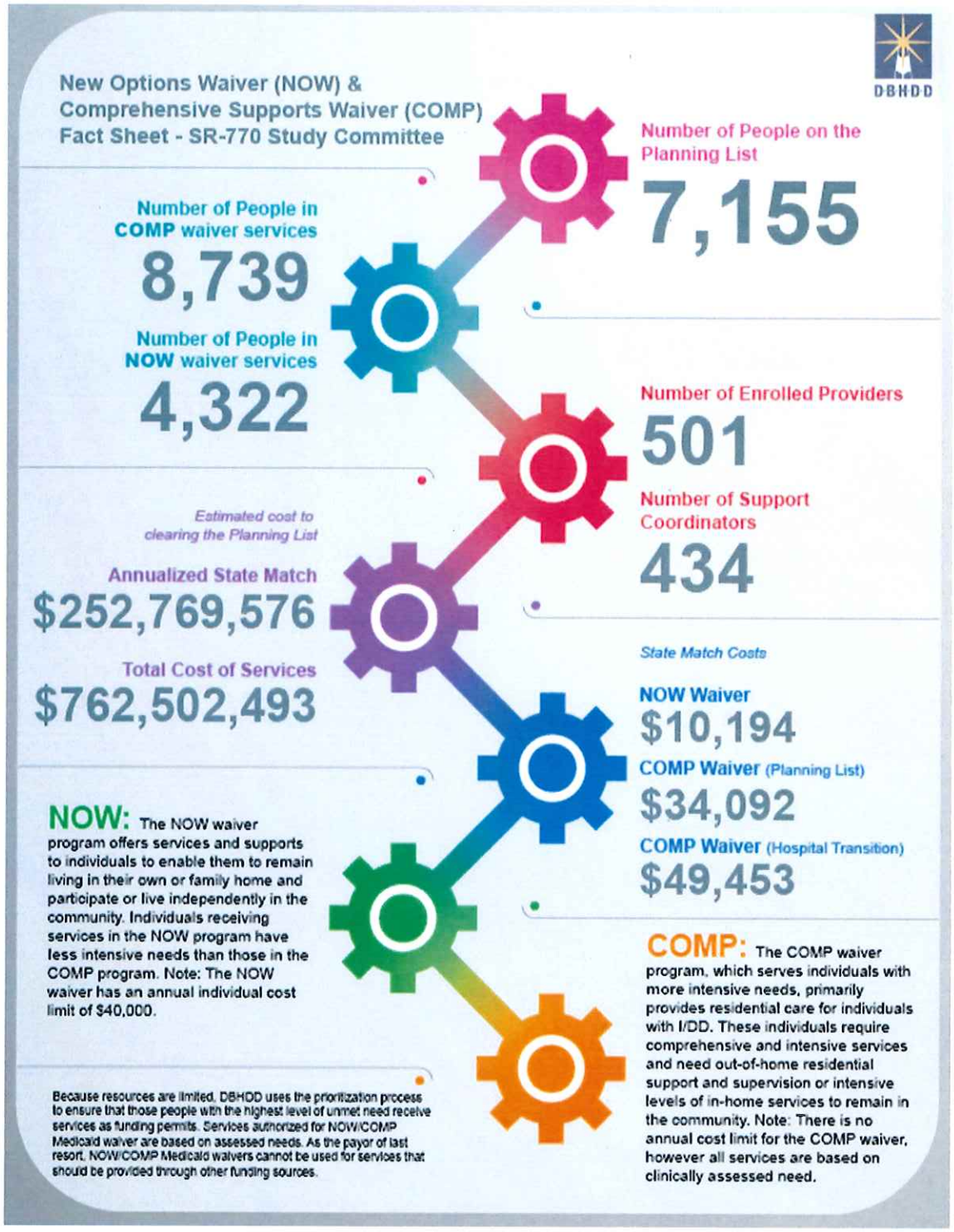
The Medicaid program is optional for states to implement. If a state decides to be a Medicaid providing state there are certain required services that it must provide. Under 1905, there is a long list of services that must be provided to eligible children. Adults also must be provided particular services including nursing home services. While this requirement may seem antiquated, Medicaid regulations also allow states to provide HCBS waivers as an offset to nursing homes because these HCBS services are cheaper and keep people in the community.

DCH indicated that waivers are not entitlements and as such states are required to have a contract with the federal government that provides exactly what they going to do and exactly how many members the waiver can cover. DCH brought the COMP waiver (which is 303 pages long) that took 14 months to re-negotiate with the federal government and has been recently approved for another five-year period. The waiver is extremely dense as it lists all available services, the eligibility requirements, the number of members that the waiver will serve, and what the financial projections are for the different services by year.

CMS will only negotiate with a single state Medicaid agency. In Georgia, DCH is the single state Medicaid agency authorized to negotiate with CMS, enroll providers, and pay for claims through DCH's Medicaid management information system. However, DCH does delegate to and recognize that that DBHDD is the lead state agency with regard to IDD experts. DBHDD conducts the day-to-day operations. The waivers contain language specifying that DBHDD has been delegated these operations. As part of the State Medicaid program, DCH has numerous quality metrics that must be reported and graded. These metrics require DCH to ensure compliance with program limitations. A major limitation that DCH must adhere to is the number of people that are in the waiver program. DCH explained that CMS reminds them that since CMS pays for two-thirds of the claims that CMS only budgets for a certain amount for the people on the waiver as indicated on DCH's projections.

DBHDD's Presentation

DBHDD provided a helpful infographic which clearly lays out the NOW and COMP waiver program waitlists and associated costs.



DBHDD began by explaining the current state of the NOW and COMP waiver programs. DBHDD explained that currently there are 7,155 individuals on the planning list for waiver services for NOW and COMP. However, currently there are 8,739 individuals receiving a COMP waiver and 4,322 individuals receiving a NOW waiver. DBHDD explained that there are currently 501 enrolled providers and 434 support coordinators or case managers for all individuals receiving a waiver. Prior to this meeting, DBHDD was asked to provide the cost of clearing the waiting list. The annualized state match is $252,769,576 and the total cost

which includes the federal portion as well is $762,502,493. These are the annualized costs. DBHDD indicated that there was another question that was asked in anticipation of this meeting regarding the annual state match cost pier waiver. The annual state match portion for a NOW waiver is $10,194. The average state match for a COMP waiver for individuals who are exiting the planning list is $34,092. The annual cost for a COMP waiver for someone who's transitioning from a hospital setting is $49,453. DBHDD explained that despite medical and or behavioral challenges, individuals with IDD continue to demonstrate their ability to live their lives in to the fullest. DBHDD emphasized that these waivers enable those with IDD to live full lives and that would not be possible without this waiver provided support and provider network.

Direct Service Professionals (DSPs) are truly the backbone of our network, as they provide direct support to individuals with IDD examples include activities of daily living like job coaching, chores, shopping, cooking, bathing, cleaning, and medication management. DSPs work with people receiving waiver services daily to help make sure that they are healthy, stable, and living meaningful, fulfilled lives in their communities. A DSP's job is the hardest job and this difficulty is not typically reflected in their wages as our median hourly wage for non-residential supports is $13.75 per hour. In residential in-home supports it is only $11.50 per hour. Of the entities who employ DSPs only 67 percent of providers offer paid time-off and health insurance is offered to only 51 percent of DSPs. DBHDD explained that this data comes from the national core indicator data from a staff stability survey of 2020, all of Georgia's figures presented today are below the national average.

DBHDD proposed some solutions to the issues facing the IDD community. DBHDD suggested that the state conduct a provider payment rate study. DBHDD has an approved spend plan initiative for a comprehensive rate study to be conducted for all NOW and COMP waiver services. The services provided above have not had a comprehensive rate review in over 15 years. DBHDD thanked the efforts of Senator Harrell, members of the General Assembly, and Governor Kemp for the passage of SB 610. SB 610 requires a rate study to be conducted every four years beginning in FY 2024, DCH and DBHED both wanted to start the rate as soon as possible. DBHDD announced that the rate study began in May of this year. DBHDD anticipates to have the results early in 2023. Presumably the rate study will yield an increase in provider rates and thus an increase to DSPs and other components of these services.

DBHDD noted that the rate study is being funded by the increased Federal Match Funding from the American Rescue Plan (ARPA). ARPA helped the Department be able to fund various opportunities and temporary initiatives which includes several temporary rate enhancements and pilots programs. However, this funding is temporary and it's crucial for us to look at rates now for more permanent solutions in Georgia so that when the temporary relief funds end, people and providers are not adversely impacted. In order to avoid a significant reduction in payment, DBHDD will need permanent rates and infrastructure to be in place and ready to go prior to the 2025 end of ARPA funding.

DISCUSSION

Senator Albers inquired about the possibility of utilizing care management organizations (CMOs) for the waiver programs to help eliminate the waitlist. DCH explained that the CMOs are going through a re-procurement as their contract cycles are expiring. DCH further explained that during this time, DCH is looking into other potential populations that could

be serviced through CMOs. DCH indicated that CMO rules are particular in the sense that there are certain populations you can just enroll under different plan options such as Medicaid for the low income population and PeachCare for Kids. This simple enrollment option becomes more difficult when trying to enroll the elderly, blind, and disabled populations because they receive supplemental social security income or are eligible based on being in a nursing home, being in hospice, or receiving a HCSB waiver. DCH explained that there are states that use CMOs. For example Tennessee. DCH explained Tennessee uses CMOs for the IDD services. However, the CMOs do not function to reduce the services or cutting off eligibility. Rather, the CMOs are good at controlling cost for the state.

Senator Albers asked about the $252,769,576 state match amount, specifically inquiring into whether this amount would clear the waiting list. DBHDDD confirmed that an additional $252,769,576 would clear the waiting list. Senator Albers further inquired into the ability of waiver programs to actually provide services. DBHDD explained that as the programs are currently being serviced, there are not enough providers to service the entire wait list.

Senator Albers inquired into the possibility of waivers having more flexibility, like allowing individuals to receive partial services while they remain on the planning list. DBHDD explained that the department has discretionary state funds that support individuals who are on the planning list. DBHDD further indicated that there may be a pathway for some individuals on the planning list to receive some supports without receiving the full robust service package provided within the waivers. Use of such funds would not be an entitlement in the way that the waivers are but there is some discretionary funding for individuals who are on the planning list awaiting waiver services. DBHDD explained that this pathway may provide an opportunity to alleviate some of the issues while long term solutions for the waivers are being implemented.

DCH explained that the $252 million state match requires the federal funding match to provide services. Without the federal match, the services cannot be provided. DCH indicated that there is not an option to pick and choose among the qualified services individuals are eligible for once they have been deemed eligible for such service. DCH indicated that once you give someone a waiver slot, there is an assessment that is done which provides these individuals with a list of services they are entitled to within the waiver. DCH explained that after the assessment is made and individuals are provided their eligible services, the Department cannot withhold services. DCH further explained that this extra light program may be possible but it would require a new limited benefit package under 1915C or making these services part of the state plan. DCH also indicated that if these services become part of the state plan, then anyone who is eligible would be getting these services without needing the waiver without limitation. DBHDD explained that the NOW wavier contains a $40,000 cap which is similar to the type of services the Senator is referring too. DBHDD indicated that through the assessments that are done, the department has some knowledge of the services needed and their costs.

Senator Harrell inquired into the 513 waiver slots that the government has funded this year. DBHDD indicated that the department is in the process of operationalizing these waivers but there is an issue with the workforce crisis. Senator Harrell asked the department to provide the number of waivers that have been awarded.

Senator Harrell asked about the possibility of obtaining statistics regarding the number of people receiving waiver awards versus the number of people actually accessing waiver provided services. DBHDD indicated that you could look at authorizations versus claims to see what individuals are being authorized for and what services these individuals are actually seeking. Senator Harrell asked for the departments to provide this information at each meeting.

Senator Albers inquired as to whether the departments could provide the cost savings that occurred when the state moved the rest of the Medicaid population to CMOs. DCH explained that they could provide the difference pre and post transfer of that population.

Senator Harrell asked for the departments to provide information on how the ARPA money is being utilized in the state.

Senator Albers explained that there are several state and local public safety departments, including EMS and fire who now have specific training on how to help individuals with IDD. They receive training on how to approach those individuals experiencing a crisis in situations that may be life or death. The possibility of coming up with a standard training that would be part of the annual continuing education credits for being POST certified as an EMT, paramedic, or firefighter would be tremendously helpful. Senator James explained that this type of training that Senator Albers mentioned should be expanded to include similar occupations such as those who work in the schools.

Committee Recommendations So Far

1. The possibility for certification/professionalization of DSPs (similar to those available for CNAs);
2. All things education to inspire people to join the industry;
3. Possible alternatives for care management organizations for waiver programs;
4. Funding;
5. Update to 1915C waiver so Georgia can offer limited services for those waiting for full services;
6. Once rate study is done, updating the appropriations amounts being sought;
7. First responders training and continuing education credits for police officers (especially those officers located at schools); and
8. Annual report to the legislature committees (health and insurance committees) regarding the status of the waitlist and waiver programs.

Meeting Two – August 24, 2022 (State Capitol)

Senator Harrell opened the meeting explaining that she authored SR 770 which established this Study Committee. She explained that this meeting's focus was going to be on workforce challenges and housing along with providing an opportunity for public comment. Senator Harrell referenced a Politico article (*See Appendix A*) that discussed the crisis in the IDD community.

DBHDD Update

DBHDD began by providing a brief overview of the entry process for the NOW and COMP waivers. DBHDD provided a hand-out containing this information. (*See Appendix B*) The first step in the NOW and COMP waiver entry process is completing and submitting an application. The application may be submitted online or at the nearest DBHDD regional field office. The second step is pre-eligibility. This is when DBHDD staff review the application and all relevant materials. The individual's pre-eligibility is determined by a psychologist's review of the documentation and a face-to-face interview if needed. The third step is the planning list, the state planning list administrator (PLA) contacts the applicant shortly after

pre-eligibility has been determined to discuss the process and complete the screening. The PLA makes appropriate referrals for supports such as vocational rehabilitation and family supports. The fourth step is funding, the most appropriate source of funding of services is identified to meet the individual's needs. A person may be recommended for the NOW or COMP waiver as well as various state-funded programs. The fifth step is waiver eligibility. Here individuals are reviewed by Aliant/Georgia Medical Care Foundation (GMCF) to determine level of care for eligibility for the NOW or COMP waiver. The sixth step is evaluations, this is when assessments are required to ensure that an individual's specific needs are met by the proper supports. The seventh step is individual service planning (ISP), the PLA along with any identified service providers complete the first annual plan which identifies the goals and the services based on the individual strengths and assessed needs. The final step is service entry, here the individual begins receiving NOW or COMP waiver services as appropriate.

DISCUSSION

Senator Albers explained that he often heard of the difficulty individuals and their families have navigating the waiver process. He inquired into the possibility of being able to make the process easier. DBHDD explained that the department has made the application available online to fill-out and submitted which has substantially increased an individual's ability to access the application process.

Senator Harrell inquired into the additional waivers that have been funded this past session. DBHDD explained that in July alone there have been 31 waivers awarded. She asked how long the eight step process takes an individual to go through. DBHDD indicated that the time table varies for each individual depending on the type of assessment that an individual needs. However, DBHDD explained that typically the turnaround time on this process is a couple of weeks. Senator Harrell asked that the department keep the committee updated on this information.

Senator James inquired into the demographics of the individuals receiving the current waivers. She specifically asked the portion of the waiver population that is African-American because there has been constituent concern that no African-Americans are receiving waivers. DBHDD explained that while they do not have the exact numbers on hand, they are aware of African American individuals on waivers. They further indicated that the waivers are determined by priority which does not necessarily account for the time an applicant has been on the waiting list. Rather, the prioritization is based on the need of the services. DBHDD also explained that the prioritization is done annually but that changes in conditions would warrant an earlier re-evaluation.

Direct Service Providers and Workforce Issue

Diane Wilush is the CEO of United Cerebral Palsy of Georgia and South Carolina. Additionally, she is the administrator of Service Providers Association for Developmental Disabilities (SPADD). She began by explaining that the recommendations of the Study Committee will not have their intended effects as long as there is a lack of proper staff to deliver services. Ms. Wilush noted that DBHDD has worked to help providers stabilize and provided support to those seeking services.

She explained that DBHDD and DCH have designated $27 million dollars of ARPA money to develop career paths and credentialing for DSPs. Over 37 million dollars of ARPA money

has been designated for rate increases for providers. Ms. Wilush indicated that the challenge with ARPA dollars is that they are temporary funds which must be spent by March 31, 2025. This means that whatever money gets pushed out to providers to pay DSPs can only function as bonuses, sign-on bonuses, or retention bonuses because providers cannot adjust wages permanently due to the money being temporary.

Ms. Wilush explained that the hand-out she provided comes from the National Core Indicator Staff Stability Study. (*See Appendix C*).[7] She indicated that it is a well-regarded study, conducted annually, that looks at all components of workforce issues across the country. The study takes a national approach, allowing states to measure themselves on national averages.

She referenced a recent US Department of Labor statistic report which states that the workforce in general has been constricted by another 600,000 people. Georgia's DSP turnover rate is on average 43 percent. Georgia's job turnover rate as a whole was 46.7 percent in 2020. She explained that 13.8 percent of DSPs leave within the first six months. Of full-time DSPs, 8.5 percent leave within the first six months of employment.

Another significant consideration to take into account for what constitutes a competitive wage for a DSP is the array of services and help that they provide. For example, DSPs serve as teachers, record keepers, housekeepers, coaches, chauffeurs, dieticians, medication technicians, and managers. Ms. Wilush explained that the rate formula currently used to determine a DSPs wage comes from a 2015 rate calculation which set the wage at $10.63 per hour.

She explained that some service providers are paying $16.00 per hour, paying finder's fees, and paying signing bonuses. These efforts are still unable to attract applicants. She indicated that since 2020, one-third of DSP positions have been vacant. She further indicated that within the last two years, 2.9 million dollars has been spent on bonuses and incentives. This spending has not attracted workers to the field

Ms. Wilush had some recommendations for the Study Committee which included:

- Amending the wage rate for DSPs to $15.00 per hour which is a 6.2 percent increase ahead of the rate increase;
- In 2025, fully funding what the rate study reveals;
- Putting IDD services in a COLA system similar to nursing homes so that rates are analyzed and adjusted every year;
- Developing a standard occupational class for DSPS;[8] and
- Supporting a housing subsidy supplement for individuals in services so that they can live where they chose to live.

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[7] Ms. Wilush explained that the data for 2021 is not available so the hand-out is reflective on the data from 2020.

[8] Ms. Wilush explained that it is important when you look at developing a rate in the department of labor bureau of vital statistics there is a standard occupational class for every single job in the country. However, there is not one for DSPs which provides a challenge in developing rates around the value and what do providers pay DSPs. She explained that often providers piecemeal and take snippets of lots of different related groups.

New Research on Community Supports in Crisis

David Whittenton explained that his objective in testifying before the Study Committee was to draw attention to the lack of infrastructure. He explained that infrastructure is needed in this industry in order for providers to provide support services such as housing facilities and day programs. He further explained that non-profit providers have to compete with for-profit organizations for spaces which are often sold at market rate. The IDD industry is a pioneer industry, this results in a lack of ongoing capital planning lenders, creditors, equity providers, and investors.

He indicated that one of the barriers facing the industry is the different compliance models. Another barrier facing this industry is staffing issues. He indicated that just raising the rate is not going to fix the problem.

Mr. Whittenton indicated that his expertise is in housing and infrastructure. Specifically, in putting together a capital plan and getting a project started by conducting necessary discussions. He gave an example of one of his recent projects, completed in the early part of 2019. He explained that the project used private capital foundations; private donations; pre-construction funding from grant funds; USDA CF Facility Funding; grants; tax-exempt bonds; and non-profit REIT money. He also indicated that building these facilities is a time extensive exercise. He explained that the demand for facilities has increased as the baby boomers age along with younger generations expecting to have options with regard to where they live and how the live their lives. Mr. Whittenton recommended that the state seek a balance among waivers, employment, and infrastructure.

DISCUSSION

Senator Harrell explained that the state has not worked on the issues of housing and infrastructure. She indicated that a possible solution would be the establishment of a work-group to address and collaborate with various experts on possible solutions.

She referenced Ms. Wilush's recommendations regarding the possibility of having a housing subsidy. Senator Harrell inquired if subsidy would help. Mr. Whittenton explained that this kind of supplemental subsidy would help. He also explained that SSI and SSDI are two different funding sources that each have a capped amount that does not provide for housing configurations. He indicated that there is a HUD program called HUD 811 which is a rental assistance program. He further indicated that federal legislation is pigeonholing this money, even though it is housed under DCA. He provided an example that is underway in Florida to revamp these subsidies to provide capital funds for individuals to assist with their rent and cost of living.

InCommunity

Whitney Fuchs is the CEO of InCommunity. He began his testimony with a quote from a special publication by Time Magazine called *The Future of Work*: "increasing numbers of Americans see no value, no virtue in jobs considered menial and unpleasant and they are rejecting these jobs in great quantities." He explained that it takes a special person to engage in DSP work. He also indicated that the US and Georgia are at virtual full employment. DSP jobs are not being filled because there is no incentive in the DSP field when competitors are paying upward of $15-20 per hour.

He explained that InCommunity is one of Georgia's largest service providers to individuals with IDD, serving over 1,700 people annually. InCommunity is consistently understaffed, currently they have 167 openings.

Mr. Fuchs indicated that 43 percent of their staff openings are in North Fulton which represents only 17 percent of the people his company serves. For InCommunity, the ability to provide housing for their employee is key because without it employees are forced to travel long distances to work. He explained that employees who work in North Fulton commute from Conyers, Fairburn, and Union City. He also indicated that it is not feasible for employees to commute between 40 and 50 miles each way every day for a salary of $12 per hour.

He explained that his organization cannot afford to pay competitive wages. . InCommunity's beginning wage is $12 per hour with the potential of $14 per hour in certain areas. The hourly wage that InCommunity pays DSPs has not been adjusted since 2014.The retention of frontline supervisors is a major issue, these supervisors are leaving the industry once they obtain management experience for retail jobs

In December of this year, InCommunity gave notice to the State of Georgia that the company could no longer provide nursing supports because it had lost $500,000 a year over the last four years delivering these services. Mr. Fuchs explained that it is not just DSPs that need wage support but the whole waiver system needs a complete overhaul on regarding service delivery costs.

Mr. Fuchs explained that Georgia is pretty stable because it has not lost too many providers. However, these providers have lost capacity, meaning that options are not as readily available for funded waivers.

He indicated that if providers do start going out of business, the safety net is crisis services centers. Crisis services centers under the same system are also full and underfunded. Emergency rooms are now functioning as temporary and immediate care when providers cannot provide services, this results in increased strain on the underfunded crisis system

Mr. Fuchs recommended that the state seriously invest in rate reimbursements, explaining that there are some red states which have increased their rate reimbursement to 25 percent.

Community Advocate

Heidi Moore was unable to attend the meeting in person but provided her testimony in writing. (*See Appendix D*).

Anna Bullard was also unable to attend the meeting to provide information regarding Ava's law. However, Senator Albers provided a brief overview of the law and some background information.

Public Comment

There was public comment at this meeting. The following people testified:

- Susan Boland Butts, Hope Service Center;
- Ryan Whitmire, Developmental Disabilities Ministries;
- Lorraine Price, Destiny's Child;

- Celeste Chippero, parent of individual with IDD;
- Barbra Schipan, sister of individual with IDD;
- Christina Henry, Never Too Late and parent of individual with IDD;
- Nancy Knight, SMILE;
- Cindy Levi, AVITA and Georgia Association of Community Service Boards;
- Scott Williams, advocate;
- Deborah Hibben; parent of individual with IDD;
- Shannon Spencer; parent of individual with IDD;
- Anna Callie Moore, self-advocate with disability;
- Kate Oubre, parent of individual with IDD;
- Sue Gaffinery, parent of individual with IDD;
- Laraleigh Windor; parent of individual with IDD;
- Julia Forester, sister of individual with IDD;
- John Soller, parent of individual with IDD;
- Stephen Feather, parent of individual with IDD; and
- Welsey and Andrea Ford, self-advocate and parent of individual with IDD.

The speakers during the public comment provided insights into their work in the IDD industry and/or their experiences as a caregiver for or an individual with IDD. For clarity, the public comment section will highlight the main concerns and issues voiced by various individuals.

A major and consistently referenced concern, was the important role DSPs play in the lives of individuals with an IDD. DSPs provide these individuals with the ability to live their lives as they want to. There were numerous concerns voiced in regard to DSP compensation. Ultimately, there was a consensus that the DSP industry needs a wage increase to remain competitive in the job market.

Another concern voiced by some family members of individuals with an IDD is how difficult it is to get help for these individuals. A constituent recommended the possibility of allowing a caretaker compensation model for parents who care for their children. Additionally, there was support for Appendix K exceptions which allowed families to be hired as caretakers.

Another concern was the lack of information being circulated in regard to the waiver programs, resulting in children aging out of school without adequately prepared caregivers and services in place.

Meeting Three – September 21, 2022 (Rome, GA)

Senator Albers opened the meeting and explained that while the Study Committee's official name uses disability, there needs to be a change in the way we think of these individuals.

DBHDD's Update on On-Boarding Families

DBHDD began by reviewing the number of NOW and COMP waivers that were awarded in July which was 31. DBHDD explained that in August 52 individuals were added to the waivers.

DCH's Update on ARPA

DCH stated that there have been inquiries into how the Department is handling the additional funding from ARPA. DCH noted that they have generated a handout referencing their website and where interested parties can track the Department's use of ARPA funds.

As part of ARPA, states are allowed to draw down additional federal funding. In Georgia, Medicaid is two-thirds federal and one-third state tax dollars. This ratio can vary among the states. ARPA allows states to draw down an additional 10 percent for HCBS in tax dollars. In Georgia, the ability to draw down an additional 10 percent frees up 10 percent of state funds which the state can use on something else. Additionally, ARPA allows the funds to go from April 1, 2021 through March 31, 2022. The initial draw will change as more claims come in and get pulled out of the system. However, the actual amount drawn down will probably be slightly more money than the amount that the Department anticipates which is $191.9 million dollars. As far as funding under ARPA, DCH has $191.9 million to spend. This ARPA funding does come with requirements.

For example, the money must be spent on HCBS. The money cannot be spent on dentists, hospitals, or nursing homes because it comes from claims DCH paid out for HCBS. Thus, the money needs to be reinvested into those services. Likewise, it has to be sustainable or a one-time payment for providers. However, something like a rate adjustment has to be sustainable in order to be funded through ARPA money. Since these funds must be spent by March 31, 2025 or they go back to the federal treasury, DCH is unable to provide permanent rate adjustments. Another important aspect that the Study Committee and the public should keep in mind is that the manner in which this money is going to be spent is not finalized because the Department can update the plan every quarter. This is useful because it provides the Department flexibility to amend their plan as needed so long as they get approval by CMS.

DCH provided a brief overview of the current plan for the money. DCH explained that to date the Department has only spent about $14 million resulting in a lot of money being in reserve. DCH indicated that they plan on building a new case management solution for the other waivers including the elderly and disabled waiver and the ICWP waiver because NOW and COMP already have a case management system.

Another area that DCH plans to improve is their critical incident management system. Currently, DCH has an online system for the submission of critical incidents but it is not as robust or user-friendly as necessary. DCH would also like to provide a new service that would pay for in-home behavioral support aides for all children under the age of 21. This idea is currently pending for approval with CMS. The program provides for behavioral support aids for families in their homes. DCH implemented autism therapy via behavioral health aides in 2018, this program was of great benefit to the families of children with autism. DCH learned that many families with children under the age of 21 need this type of in-home help to assist with things like skill building; allotment issues; and self-harm issues. The Department has introduced this idea to CMS. Georgia would be one of the first states in the nation to offer this type of service.

DCH is attempting to conduct a technology expansion to increase assistive technology in the waivers. The Department is addressing many workforce development training issues and providing additional intensive family support dollars. DCH is conducting a rate study on their-side for the elderly and disabled waiver and ICWP waiver. Likewise, the Department is currently conducting a rate study for the NOW and COMP waivers as well as for mental health services. DCH explained it has not done a rate adjustment for Medicaid mental health and addiction services since 2008. DCH also did a ten percent rate increase for the Georgia Pediatric Program which provides in-home skilled nursing and personal support services for children. Additionally, DCH is funding a supported employment pilot with DBHDD.

DISCUSSION

Senator Harrell inquired into the rate increases for providers. DCH explained that there are two different rate increases. There is a five percent rate increase for all services and an additional two percent rate increase that was allocated by the legislature. As of September 16, 2022, the Department will have all of the prior authorizations updated for the initial five percent rate increase at which point they will begin a mass adjustment to pay out providers going back to July 1st for when the rates went into effect. Providers will receive that money as part of a mass adjustment. At this point, DCH is not certain about the payment timeline. DCH has asked the Georgia Medicaid Management Information System, which processes these claims, to make this a top priority and expedite the process.

Avita Community Partners' Update on IDD Services

Cindy Levi is the CEO of Avita Community Partners which is one of Georgia's Community Service Boards (CSB). In 1993, the state established CSBs through legislation to act as a safety net of providers for mental health substance use and intellectual and developmental disabilities. Ms. Levi has been in the IDD industry for 40 years. Georgia has a one to ten ratio and there are providers that are struggling to have what they need to be able to support the individuals. Avita had seven self-advocates provide testimony on behalf of themselves and their CSB. Their testimonies explained the services that the CSBs have provided them and that its impact on their lives. Ms. Levi explained that while the rate study is great, the Departments should not forget about the human aspect and allow for verbal input as the process continues.

Advocate Phillip Wood

Mr. Wood echoed the sentiments of Diane Wilush and Heidi Moore from the previous meeting. He indicated that there is a debate occurring with regard to what critical issue needs to be addressed first; whether the waiver funding or the workforce issue needs to be prioritized. He explained that both of these issues are equally important and that both need to be fully funded. He explained that the IDD community has taken small concessions for the past decade and that the State needs to be thinking bigger than 513 waivers in one year as that number only addresses five percent of the wait list. His recommendation is to double the number of funded waivers.

The idea that the DSP matter needs to be resolved before funding of the waivers can happen will result in unhappy families who are told they need to wait even longer until this matter is resolved. He explained that when his family received the waiver it was a huge relief. However, they now experience issues with being able to have adequate support staff along with a huge lack of programs for their son Evan. He further explained that if the state

budgeted for an additional 1,000 persons to receive a waiver then many would use self-direct which would allow for a greater pool of support staff candidates and more flexibility to pay a viable DSP wage to quality support staff.

Another concern that is being discussed is the efficacy of day programs versus work programs. One policy position is that people with all types and severities of impairments can work. Another position is that not all persons can effectively work even with the proper support tools and customizations, requiring quality and accessible day programs.

As for family members as DSPs, Appendix K needs to be made permanent. There are similar programs in 16 different states in the US. Family members need to be paid especially while there is a DSP shortage. Family members are more dependable, have a vested interest in the individual, and are more understanding of an individual with IDD's needs than anyone.

Mr. Wood explained that if this truly is a bipartisan issue, both Democrats and Republicans need to come to the table to fix these problems. He indicated that the IDD community needs to demand that all of the programs available be fully funded and that if they are not then the community may need to take legal action. He explained that families want (1) off the waiting list and to have waivers; (2) better day programs and when appropriate work programs; and (3) the DSP crisis addressed including permanent family caregiver support staff compensation.

Public Comment

There was public comment at this meeting. The following individuals commented:

- Steven Hunt, Briggs and Associates;
- Dave Lamb, Home Care Association of America–GA Chapter;
- Linda Mincey, parent of individual with IDD;
- Robin Davenport, Mineral Springs Center;
- Jason Cook, self-advocate and cross plains community partner;
- Elizabeth Hunter, Cross Pains Community partner;
- Jim Givens, parent of individual with IDD;
- Barbara Monday, DIGS Inc.,:
- Jenny Dalton, Chattooga Co. Sheriff's Office;
- Jacob Allmon; FTC;
- Antoine Posey; FTC;
- Shacreta Green; FTC;
- Tiffany Abbott, parent of individual with IDD;
- Brandy McConnell, Georgia Chamber of Commerce Resource Center;
- Debbie Sheary, family member of individual with IDD;

- Dena Payne, IDD provider;
- Nick Sulaiman, RHA which is a CSB;
- Jenny Shey, Network Day Service Center;
- Kenneth Crawford, citizen;
- Sonja Johnson, Wood Right industries;
- Joan Ware, parent of individual with IDD;
- Pat and Madeline Patrone, parent and self-advocate of individual with IDD;
- Julia McGuiness, family member of individual with IDD;
- Bradley Carlisle, family member of individual with IDD;
- Mary Kimberough, parent of individual with IDD; and
- Written testimony from 15 individuals from the Mineral Spring Center, Inc.

The speakers during the public comment provided personal insights into their work and experiences either in the IDD industry or having a family member with an IDD. For clarity, the public comment section will highlight the main concerns and issues voiced by various individuals.

A concern that was voiced by some individuals is the lack of transportation options for individuals with and IDD. The issue is pertinent when individuals are connected to employment opportunities but are unable to obtain transportation and thus unable to work.

Similar to the last meeting, there were numerous individuals who expressed their concern about the DSP crisis, specifically in regard to wages. Individuals explained that even those who do get waivers are sometimes unable to connect with providers because of the staffing shortages.

Another concern expressed was the difficult process parent's face in becoming the legal guardians of their children with an IDD after they age out. Along this same line, there is an issue with the transition for individuals with IDD from aging out of school to receiving waiver services. The problem is that often families are unaware of the waiver process and the potential long waiting periods to receive services once the waiver has been granted.

Meeting Four – October 19, 2022 (Tifton, GA)

Senator Albers opened the meeting at Tifton Regional Medical Center. The turnout required the Study Committee to set up an over-flow room.

DBHDD's Update

DBHDD provided two up-dates regarding waiver admissions. DBHDD explained that along with the 31 waiver awarded in July and the 52 waivers awarded in August, the Department awarded an additional 52 waivers in September which brings the total number of waivers to 135 since the beginning of the new fiscal year which began in July of 2022. The second update is related to the 5% rate increase for providers under NOW and COMP. As of July 6, 2022, all claims providers are billing and receiving include the five percent rate increase.

DBHDD explained that the challenge is with regard to the retro-payments. DBHDD provided some context to the rate increases. She explained that typically the rate increases would go into the base NOW and COMP waivers. DBHDD indicated that the state could no longer wait for the COMP waiver to come back down before the Department started acting. Therefore, DBHDD decided to make full use of a temporary Public Health Emergency waiver called the Appendix K to get that appropriation faster which is allowed is applied retroactively. Considering that the base waivers do not guarantee the ability to act as such, if the Department had used our base waivers that five percent would likely still be pending Federal approval since there is no guarantee that it was going to go retro.

Appendix K was and is still the fastest mechanism for the five percent rate increase. This five percent rate increase was approved March 9, 2022. This date is where the Department begins its clock because DBHDD's rate increases had to be approved by CMS before it could do anything regardless of the state appropriation. DBHDD emphasized that there has never been a scenario where every single service for every single payment for every single person receiving a NOW or COMP waiver has had to go back an entire year for payments. This is because DBHDD has never had that option before the Public Health Emergency. This decision to apply the rate increases retroactively is the first time DBHDD has ever done something like this. Moreover, it is something new and difficult on its systems because there are approximately 27,000 authorizations and 1.6 million lines of code that need to be reviewed. Such work was a shock to the billing systems which had never had to support this type of action before because it was not allowable.

DCH's Billing System plans to begin reprocessing the NOW and COMP retro claims in early December with the intention of being finished by the end of the calendar year if not sooner. The reprocessing of these claims will be prioritized by oldest claim first based on the original reprocessing date and future billing guidance will come out for providers on certain specialty claims. DBHDD further explained that no action is required from providers to receive the five percent.

SPADD

David Wilber is the director of Diversified Enterprises and president of SPADD. He explained that his objective was to provide recommendations for the Study Committee. They are as follows:

1. Proper funding for supported employment that includes long-term support for employees along with adequate funding for transition of school age children that age out of school. National Studies have demonstrated that supported employees return an average monthly net benefit to taxpayers of $251 and generate $1.46 for every dollar spent. It is a good investment for a business friendly state;

2. Waivers should include flexibility, a day in the life is not a straight line and our current waivers do not allow for the fluidity that is life. An example would be a day that may include some work, some day program, and some secondary education. The important aspect that the waivers need to provide is the choice for individuals to determine what they want;

3. With regard to the waiting list, several states are using their waiver light option which would probably be like Georgia's NOW waiver to address waiting list issues because not

everyone needs the $80,000 waiver option. Some people just need day services or in-home services to support the family nucleus to keep people healthy. Some states have successfully driven down and strategically eliminated their waivers waiting lists by using their waiver light option;

4. With regard to delays in opening residential locations, legislators ought to understand the Georgia Collaborative Administrative Services Organization ("CASO") that is under contract with DBHDD. CASO is the vetting agency that allows providers to open new residential services such as group homes and host homes. It is not an exaggeration that it takes over a year to open a new residential option; and

5. With regard to the current rate which is built on $10.63 per hour, such rates create a staffing crisis in today's economy. The rate studies demonstrate a need for wage rates to jump substantially from $10.63. SPADD recommends that the state fully fund the rate study in FY 24-25. Additionally, SPADD recommends that the state rate increase by 6.2 percent in the 2023 legislative session as a good faith down payment toward the $15 per hour rate.

It is not special to need a place to live, something meaningful to do with your day, to have a job, and someone to care for your needs. He ended his testimony with a quote which states "a civilization is measured by how it treats its weakest members."

DISCUSSION

Senator Albers explained that when you look at the totality of those on the waiting list that that a large majority do need a lighter service such as day services. He further explained that when the Study Committee addresses these matters it is critical to separate those who have extraordinary needs versus those that have lesser needs.

Public Comment

There was public comment at this meeting. The following individuals commented:

- Hilary Vece, Georgia Coalition for Family Advocates;
- Dana Lloyd, Georgia Advocacy Office and partner with GCDDD;
- Caroline Chandler, Aspire BHDD, member of SPADD, and parent of individual with IDD;
- David Lamb, Georgia Chapter of Home Care Association of America;
- Dr. Michael Warn, Mercer University,
- Quentin Jackson, individual with an IDD;
- Ratiel Sheperd, individual with an IDD;
- Steve Jaramillo, CARC;
- Sheila Jefrey, individual with an IDD;
- Stephen Smith, CSB of Middle Georgia;
- Connie Bryant, CSB of Middle Georgia;
- William McClardy, CSB of Middle Georgia;
- Harry Hamm, Lowndes Advocacy Resource Center;
- Lauren Gray, Georgia Occupational Therapy Association;
- Dr. Kay Eady, parent of individual with IDD;
- Jenifer Stephens, Aspire BHDD;
- Danny Hoover, Uniting 4 Change;
- Lynn Platt, family member with an IDD;

- Cameron Bishop, Wesley Glen Ministries;
- Tom Bauer, GOTA (*See Appendix E*);
- Amanda Manchester, Lagacy BHS and individual with an IDD;
- DeAnne Julian, Arc Southwest Georgia;
- Quadonna Hamilton, Lagacy BHS and individual with and IDD;
- Marian Jackson, Jessamine Place;
- Andrew, individual with IDD;
- Kakeria Thomas, employee of Georgia; and
- Carolyn Brevard, employee of Georgia Pines.

The speakers during the public comment provided personal insights into their work and experiences either in the IDD industry or having a family member with an IDD. For clarity, the public comment section will highlight the main concerns and issues voiced by various individuals.

The comments and concerns expressed by individuals at this meeting were the same concerns expressed at the previous meeting surrounding the wage rates; lack of information readily available to parents for transitions children from school; workforce issues; and waiver funding. Numerous individuals voiced their concerns with regard to the lack of transportation options especially in rural Georgia for individuals with an IDD. Another concern expressed by individuals were the inability to receive service even after receiving a waiver.

Meeting Five – November 16, 2022 (State Capitol)

Senator Harrell explained that the Study Committee is going to have an additional meeting for the final report adoption.

DBHDD's Update

DBHDD explained that along with the 31 waiver awarded in July; the 52 waivers awarded in August, and the 52 waivers awarded in September, the Department awarded an additional 49 waivers in October which brings the total number of waives to 184.

DISCUSSION

Senator Albers inquired about the wait list with regard the breakdown of individuals who need more traditional services versus those with extraordinary needs. DBHDD explained that it is possible to provide this break down. However, more information is need with regard to limits and requirements to qualify for certain categories.

Senator Harrell asked whether the NOW waiver was meant to be a more limited waiver as compared to the COMP waiver. DBHDD confirmed that NOW is a more limited waiver program with a $40,000 limit. DCH further explained that beyond the money limitation, NOW does not provide residential services. DCH also indicated that it would be possible to further categorize the kinds of services in lighter groups to see the costs and where the levels are located. DCH further indicated that it would be possible to further define the eligibility criteria for specific level of services.

Senator Harrell inquired into the target date to get the 513 waivers awarded. DBHDD explained that these waiver are part of the 2023 FY Budget and as such the goal is to get them all filled before the end of the fiscal year.

DCH's Update

DCH explained that the first batch of retroactive rate adjustments (*i.e.,* the five percent rate adjustments) have gone through DCH's quality assurance check and their approval process. The first batch of rate adjustments are for July 2021 through November 2021. This first batch consists of 400,655 claims which totals $12,751,643.82 paid out to providers. According to DCH, these rate adjustments should show up on a provider's electronic fund transfers (EFTs). This first batch of rate adjustments should appear this week on a provider's EFTs. The payment will go out the following week. The payment will appear in the remittance section for the reprocessed claims.

The second batch of retroactive adjustments has received preliminary approval. However, the funds still need to go to DCH's CFO and Medicaid director for approval. This second batch consists of 390,156 claims which totals $12,351,283.93 paid out to providers. The second batch of rate adjustments are for December 2021 through March 2022. DCH anticipates this second batch to be sent to providers the first week in December. The final batch will be processed through mid-December keeping the Department on track to completing the retroactive adjustments by the end of the year.

DCH indicated that while the Department pays out these rate adjustments to providers, the Department does not control how these providers choose to spend that money.

Advocate

Heidi Moore is a parent advocate of Jacob Moore. Ms. Moore provided her concerns such as: 1) the difficulty in navigating the system; 2) the long wait list; 3) wages paid to DSPs; 4) against the possibility of moving to a managed care system for IDD services; 5) low funding rates; 5) lack of flexibility of transferring funds within the waiver; 6) inadequate systems with regard to technology; 7) aging-out and transitioning an individuals from pediatric services to the waiver programs is difficult and time consuming. She used her own experience of transitioning her son into the waivers. She explained that she began the process when he was 18 years old.

Unlock 2.0

Dr. Jose Delgado spoke as part of InCommunity on behalf of Unlock 2.0. He explained that managed care has a service delivery model whose aim is to reduce program costs and provide better utilization of Health Services. This is done by contracting with CMOs. Possible CMOs include United Healthcare or Amerigroup. Nearly 20 states have planned or implemented some version of managed care for the IDD services. However, models range from multi-state commercial health plan contracts to local provider-led initiatives. He indicated that the lack of uniformity among the states is a red flag because there does not appear to be one system that is adopting consistent standards. Moreover, he explained that Medicaid managed care has been around for decades and is not commonly used among states to provide long-term services which is another indicator that such a move is not in the best interest of people with an IDD. He further explained that people with IDDs are a unique population that require a different set of services and supports than non-disabled people or even people with other types of disabilities need. Utilizing a CMO for such services may impose extra costs such as high out-of-pocket fees.

There is little research about quality standards for the managed care of people with IDD. Moreover, the majority of existing research about managed care for people with disabilities

is about health care services and controlling costs. This research does not analyze the quality of care. He provided areas that Unlock 2.0 believe warrant further investigation. They are: 1) gathering additional health research and data on effective programs for the population; 2) consideration of support needs to address multi-generational caregiver issues; 3) encouraging adults with IDD to exercise informed decision making and have their preferences honored at the managed care table; 4) seek out research and evaluation on the effectiveness of other state initiatives designed to address workforce issues; and 5) address equity issues and health disparities for people with IDD.

Georgia Council on Developmental Disabilities

D'Arcy Robb is the executive director of GCDD. She explained that GCDD's mission is to bring about social and policy changes that promote opportunities for the wide spectrum of persons/people with developmental disabilities and their families to live, learn, work, play, and worship in their communities. GCDD is a federally funded, self-governing organization charged with identifying the most pressing needs of people with developmental disabilities in Georgia. As per the federal Developmental Disabilities Assistance and Bill of Rights Act ("DD Act"), over 60% of our members must be individuals with developmental disabilities or their family members.

She indicated that developmental disability is an umbrella term that refers to a wide variety of severe, chronic, lifelong disabilities resulting in substantial functional limitations in 3 or more areas of major life activity. A person whose challenges are in language and learning has a disability that looks different from someone whose limitation are mobility, self-care, and the capacity for independent living but nonetheless, both are developmental disabilities.

She compared this definition to the eligible requirements for NOW and COMP waivers. Currently, there are two paths into receiving NOW or COMP services. One is to have an intellectual disability onset prior to 18 years of age with limitations in adaptive functioning and an IQ of 75 or below. The other path is through a related condition which means it is something that is closely related to, looks like, and functions a lot like intellectual disability.

The comparison demonstrates that the population that GCDD covers is broader than those covered under the NOW and COMP waiver eligibility requirements. Prevalence rate study shows Georgians with IDD make up approximately 1.58% of the population or about 170,640 Georgians. However, more recent State of the States shows there are approximately 226,000 caregiving families supporting someone with IDD in Georgia. She indicated that in Georgia approximately 6% of families are providing care for a family members with intellectual or developmental disabilities.

As of this August, Georgia had over 13,000 individuals receiving NOW and COMP waivers with over 7,100 folks on the waiting list. If you analyze the two sets of numbers it becomes apparent as to why there are such drastic numbers. It is because of the waiver criteria which results in individuals with developmental disabilities not able to qualify under NOW or COMP.

The data from State of the States, demonstrates that Georgia's spending on IDD services is significantly lower than the rest of the nation with regard to fiscal efforts. Additionally, Georgia is low among our neighboring states in the Southeast. Georgia is behind Kentucky, Arkansas, Louisiana, Mississippi, South Carolina, North Carolina and Tennessee.

She recommends that there be a shift to economic development tools which allow family members to keep their jobs. Additionally, businesses become providers because they can pay people a livable wage which results in money being pumped back into the Georgia economy.

She indicated that other states are catching on to this reality of waivers being an economic development tool because states like Arkansas and Oklahoma over the past year have ended their waiting list. While Florida has not ended their waiting list, they have put major investments into it which has allowed them to move thousands of people off the list.

She provided Short-Term Advocacy and Strategies for 2023. She recommends that the Georgia General Assembly add an additional 1,000 new NOW and COMP waiver slots; funding to increase DSP wages to a minimum of $15 per hour; and update the long-term developmental disability services plan.

Additionally, she provided medium to long-term recommendations which are:

1. End the wait list, meaning the state fully fund NOW and COMP wait list and maintain a focus on ongoing waiver needs;
2. Keep DSPs at a livable wage to support Georgia families and businesses;
3. Centralize Employment First in waivers and services;
4. Work to maximize resources in a way that supports individuals with disabilities and their families;
5. Consider potential Medicaid care model changes with great diligence; and
6. Develop long-term, person-and family-centric service evaluation model to ensure HCBS services are appropriate and meaningful for Georgians with ID/DD and their families.

Advancing Employment

Doug Crandell works at a GCDD funded program. The program is called Advancing Employment. He explained that households in the United States represent $68 billion dollars' worth of purchasing power if they have a member with an IDD. Every person with an IDD that goes through supported employment returns to taxpayers over $3,000.00 every year.

Using the National Core Indicators, in Georgia 70 percent of the individuals in the IDD service system attend a day program or a sheltered workshop. In Georgia it is still legal to pay workers with disabilities sub-minimum wages. The national average of individuals in the IDD service system that attend a day program or a sheltered workshop is 42 percent. In Georgia only 13 percent and nationally 27 percent of individuals with an ISP in their service plan have getting a job as a goal.

He explains that Georgia needs better support coordination in terms of understanding employment supports accommodations, customizations, and supported self-employment. He further suggested two policy imperatives. They are: the first is "State is Model which means state agencies employ and provide accommodation and customization for individuals with IDD. Demonstrating the ability to employ individuals with IDDs allows the state to say to private businesses we are doing it too. Georgia does not have "State as Model employer. The second imperative is to create a state-specific tax incentive that goes directly to employers hiring individuals with IDDs.

Public Comment

There was public comment at this meeting. The following individuals commented:

- Rita Young, Unlock 2.0;
- Kim Weinrer, parent of individual with IDD;
- Holland Post, parent of individual with IDD;
- Nancy Knight, SMILE;
- Tais Keyser, parent of individual with IDD;
- Cindy Levi, Avita and GACSB;
- Suzanne Lothanius, parent of individual with IDD and Every Voice Matters;
- Houston Asher, individual with IDD;
- Katie Asher, parent of individual with IDD;
- Sid Besmeatonik, family member of individual with IDD; and
- Rochelle German-Stru, parent of individual with IDD.

The speakers during the public comment provided personal insights into their work and experiences either in the IDD industry or having a family member with an IDD. For clarity, the public comment section will highlight the main concerns and issues voiced by various individuals.

Individuals suggested that Georgia develop new NOW and COMP waiting list that contains its own criteria aimed at helping to reduce the number of people on the waiting list.

Similar to all the other meetings, individuals repeatedly encouraged the State to adequately fund these waivers, services, and programs. Another continuing theme was the need to provide proper education to families with regard to the aging-out process and need to plan for transitioning children into the waivers.

Meeting Six – December 14, 2022 (State Capitol)

The Study Committee discussed and voted upon this Report and Recommendations, which received unanimous approval from the Study Committee members present.

FINDINGS AND RECOMMENDATIONS

Based on the testimony and research presented, the Study Committee on People with Intellectual and Developmental Disabilities and Waiver Plan Access recommends ...

Strategic and Long Term Planning

1. Create the IDD HCBS Commission on Reform and Innovation (Commission). Within the Commission create working sub-committees on issues regarding Managed Care; Workforce Wages/Incentives and Direct Service Provider Career Paths; Transportation; Housing; Employment; System Management; Innovation and Technology Processes; Service Delivery Innovations and Technology; Planning List Management and Funds Utilization/Evaluation; and other committees as needed. The Commission membership should include, but not be limited to, families; providers; subject experts; self-advocates; and relevant state staff;

Waivers and Services

2. Fund 2,400 additional Waiver Slots in the FY 2024 budget;
3. The Commission is to research Managed Care delivery of services for those with IDD, determining the viability of a Managed Care approach for funding support and services for this population. If determined viable, Commission would guide/oversee the development of a Managed Care for IDD–Georgia Pilot Plan, assuring the inclusion of all stakeholders including families, providers, and the GCDD, in crafting the plan;
4. If a pilot is determined viable, such a pilot should consist of no more than one percent of the NOW and COMP HCBS census (which is 130-150 individuals). The participants will be those individuals who are being newly enrolled in NOW and COMP waivers during the pilot implementation year. The pilot participants must represent a proportion (of the waiver census) by region and waiver type (NOW and COMP). The individuals would receive that NOW or COMP service needs met via the Managed Care pilot;
5. Work with the Employment First Georgia Council as created by 2018 Georgia' Employment First Act, as well as the Georgia Vocational Rehabilitation Agency, to ensure that "competitive, integrated employment is the first and preferred option in the provision of publicly funded services for all working age citizens with disabilities" (HB 831, 2018). Centralize Employment First in waivers and services and maximize resources in a way that supports individuals with disabilities and families;
6. Develop a long-term, person-and-family-centric service evaluation model to ensure HCBS services are appropriate, meaningful, and easy to access for Georgians with IDD and their families;
7. Utilize the ARPA rate study and future Home and Community Based Waiver rate studies to inform the legislature on rate adjustments to providers;

Workforce

8. Utilize the ARPA rate study and future Home and Community Based Waiver rate studies to inform the legislature on rate adjustments to providers;
9. In order to assure an adequate workforce of DSPs, utilize public testimony, feedback from consumers and providers, as well as current and future DBHDD Rate Studies, to determine a wage increase in the 2024 budget. Continually evaluate DSP wages to ensure they are adaptable and competitive, and are enough to cover DSP transportation and housing needs (cited in testimony as being obstacles to recruitment and retention). Consider how to provide additional incentives such as healthcare, retirement benefits, and other innovative recruitment and retention methods in order to reduce turnover;
10. Work with the Federal Congressional Delegation to create a Bureau of Labor Statistics "Standard Occupation Classification" for DSPs;

11. Utilize the Commission Sub-Committee structure to support and complete the work of the existing DBHDD workgroup on DSP Career Paths. Determine the most effective implementation of *various* credentialing models, recognizing that *requiring* credentialing can exacerbate workforce challenges. Assure adequate funding to employers to enable a pay rate incentive for completion of a credentialing model;
12. Develop and implement a mechanism for paying wages to family caregivers pending federal approval;

Administration

13. Refine the Waiver Planning list to reflect easily accessible data, which supports objective decision making and future projections for planning. This data should include categories such as acuity/level of care, current supports, current needs, age, region, and projected date of service needs (*i.e.,* 3 years vs immediate). The data must be in a format that allows for easy access and sorting/searching by the public; and
14. In order to have the financial tools and data to allow for thoughtful and precise decision making and planning by both the General Assembly and DBHDD, quarterly reporting on IDD legislative allocations, spent FY to date and plan for use of lapse each quarter should be reported to the Commission and well as the House & Senate Appropriation Committee Chairs.

Respectfully Submitted,

FINAL REPORT OF THE SENATE ON PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES AND WAIVER PLAN ACCESS STUDY COMMITTEE (SR 770)

Senator John Albers – Committee Co-Chairman
District 56

Senator Sally Harrell – Committee Co-Chairwoman
District 40

APPENDIX A

THE FIFTY

‘People will die waiting’: America’s system for the disabled is nearing collapse

Providers for intellectually and developmentally disabled struggle to recruit and retain staff amid soaring inflation, pandemic burnout.

A coalition from #bFair2DirectCare, who care for people with disabilities, protest for competitive wages prior to the start of then-New York Gov. Andrew Cuomo's State of the State addresses in Albany, N.Y., Jan. 11, 2017. | Hans Pennink/AP Photo

By **DAN GOLDBERG**
08/10/2022 04:30 AM EDT

Private agencies that provide services for the intellectually and developmentally disabled have long warned that, without fresh state and federal funding, they would be unable to provide housing and staff support to the growing number of Americans who need care.

Over the last 12 months, the Covid-19 pandemic's lingering effects and once-in-a-generation inflation have turned dire predictions into sobering truths, and agency directors, who for years hobbled along on shoestring budgets, have done in 2022 what not long ago would have been unthinkable: closed their doors.

Advertisement

Todd Goodwin, CEO at the John F. Murphy Homes in Maine, has closed four group homes over the past 18 months. Until this year, residents of a home that was closing would be transferred to another home with open beds. But in February, he couldn't make the staffing ratios work — two residents, who have come to rely on the care his agency provides, would have to be sent back to their families.

"These are people who have been with us for years; we love them," Goodwin said. "They are losing their homes through no fault of their own. We have just run out of options."

In Connecticut, one provider has closed 10 group homes; in Oklahoma, dozens of residential units sit empty for want of staff; and in Texas, budgets are running increasingly in the red.

Two decades after the Supreme Court ruled states must provide care for the disabled in the least restrictive setting possible, home- and community-based service providers are floundering. Many states, flush with cash thanks to a juiced economy and federal stimulus, may need to act following years of inadequate funding that left an already fragile system on the verge of collapse.

The Fifty

In the unfolding pandemic, economic crisis and reckoning on race, governors and mayors are shaping our shared future. Who are the power players, and how are they driving politics and influencing Washington?

Full coverage »

Across the country, more than three-quarters of providers said they've turned away referrals, and more than half have discontinued programs, according to a survey from the American Network of Community Options and Resources, an advocacy group.

What happens to the residents? They live with siblings or their elderly parents, some who are themselves in need of care, or they become wards of the state, sent to live in larger and larger facilities, the kind of institutionalized settings the country swore off nearly 50 years ago.

AD

Interviews with more than a dozen providers across the country reveal a patchwork of perennially cash-strapped programs unable to recruit and retain staff, leaving desperate families on yearslong waiting lists.

Most agencies rely on state and federal Medicaid money to pay employees and can't increase salaries to compete with the retail or food-services industries because Medicaid rates are set by the state. Though that's always been a challenge, it's exacerbated during periods of high inflation when wages in other sectors rise and the cost of living increases, making it that much more tempting for employees to take a new job that pays a couple dollars more an hour.

Wages grew nearly 10 percent in leisure and hospitality over the last year, according to the Bureau of Labor Statistics, and roughly 5 percent in retail.

"With the price of gas, people can't afford to drive an extra 20 miles for a $14-an-hour job when they drive past six places that pay $15," said Angela King, CEO of Volunteers of America Texas.

King has consolidated five homes into three and is preparing a budget for her board that shows an $80,000 loss on each of those homes.

She can dip into reserves to make ends meet but for only so long, she said. Other providers delay capital improvements or offer gas cards in lieu of raises.

"I really do not see this system of care being sustainable," King said.

AD

While the workforce crisis predates the pandemic, it was also worsened by it as the number of work-from-home opportunities increased, luring employees away from jobs that tether them to residents.

“They can work for a call center, stay home and earn the same amount … and not worry about daycare,” said Barry Simon, president and CEO of Oak Hill, which provides disability services in Connecticut.

Turnover rates have climbed to nearly 50 percent nationally, meaning half of all employees need to be replaced every year, a huge expense in time and training.

Andrea Koenigsaeker, 37, rolls down a hallway July 2, 2008 in Gizmo House, a group home where she and five others live in Plantation, Fla. | Wilfredo Lee/AP Photo

Meanwhile, the waitlist of intellectually and developmentally disabled Americans who need home- and community-based services is growing rapidly, far eclipsing the ability of state governments to serve people who need help with basic daily tasks like bathing, cooking and dressing.

AD

More than 665,000 Americans are on a waiting list, according to a 2020 survey from the Kaiser Family Foundation, the most recent year for which data is available. While the way states collect and sort data makes year-over-year comparisons difficult, analysts and experts who study the nation’s waitlist say the trend is going in the wrong direction, and anecdotal evidence suggests the

pandemic made everything — the burnout, resignations and resulting inflation — worse.

“It’s just been hellish,” said Diane Wilush, president and CEO of United Cerebral of Georgia and South Carolina. “People will die waiting.”

Most states were helped by last year’s American Rescue Plan, which temporarily boosted federal matching funds for home- and community-based services. Many providers used the bump to supplement wages or offer pandemic signing bonuses, but that money was never intended to be a permanent fix.

“We’ve offered bonuses, but [employees] know that’s not permanent,” Wilush said. “When Target goes to $24 an hour, it’s really hard to compete with that.”

The Biden administration sought to shore up those programs, proposing $400 billion in new money for home- and community-based services in the Democrats’ social spending package. House Democrats put about $150 billion in their version that passed last year — but it was not included in the reconciliation package that the Senate passed this week, meaning it is unlikely

AD

Without more money to recruit and retain staff, providers believe the trend of placing people in larger group homes will accelerate. While wealthier families may be able to pay for private services, middle-class and lower-income families will likely see the quality of their loved one’s care diminish. The difference between a 4-bed home and a 12-bed home can be monumental for the resident, who is likely to receive less attention and have fewer options for recreation.

“If you have one person looking after eight people who are totally dependent or even partially dependent – and they need to be bathed and have their meals cooked – you run out of energy to do anything but basic hygienic care,” King said.

‘What is going to happen to her?’

In 1999, the Supreme Court ruled that states must provide people with intellectual and developmental disabilities services in the least restrictive setting possible — in other words, a community. What became known as the Olmstead ruling stemmed from a case involving Lois Curtis and Elaine Wilson, two Georgia women who were voluntarily admitted to the psychiatric unit in the state-run Georgia Regional Hospital. Even after their medical treatment was completed the women were confined to the institution, which they said amounted to illegal discrimination under the Americans with Disabilities Act.

The court's ruling — that states must provide community-based services when appropriate — was hailed by disability advocates as a watershed moment in the fight against institutionalization.

But 23 years later, hundreds of thousands of people with intellectual and developmental disabilities struggle to get the services they need. The court's ruling dealt a blow to institutional settings — and most states have moved away from that model of care — but did little to help smaller community-based settings flourish. The decision did not force states to pay for community-based settings, only to provide them when resources are available, a squishiness that, in part, explains the current predicament.

AD

Over time, Medicaid rates failed to keep up with rising costs, putting a squeeze on the system. Simon said he hasn't received an increase for administrative and general expenses — essentially, capital improvements — in 17 years.

Georgia, the state where *Olmstead* began, now exemplifies what can go wrong. The state has around 7,000 families on a waiting list.

Mark S., shows some of the word search books he enjoys in this April 1, 2021 photo at his Springfield, Ill., group home operated by Sparc, an agency that assists people with intellectual and developmental disabilities. | John O'Connor/AP Photo

Pam Walley sees it from both sides. She works for Georgia Options, which provides support services for people with disabilities in their own homes. Walley knows her organization can't compete with employers like Amazon that pay $20 an hour, about twice what service providers earn in Georgia.

AD

She is also caring for her 27-year-old daughter with special needs and is one of the thousands of aging parents across the country forced to ponder what will happen to their children when they can no longer bear the burden of feeding, toileting and bathing grown men and women.

"I just had my 60th birthday and I am tired and my health is failing and I'm not going to live forever," she said. "What is going to happen to her? ... I don't want her to be in an institution, I don't want her to live in a nursing home, but frankly, that's all that exists for her."

Single parents, who care for their adult children, told POLITICO of an impossible balancing act: every haircut or trip to the grocery store comes with the knowledge that they must find someone to stay home with their child or bring that child into an environment that can trigger an emotional or behavioral meltdown.

The Georgia legislature this year budgeted for an additional 413 Medicaid waiver slots on top of 100 that Republican Gov. Brian Kemp put in his budget. That's a record number, said Democratic state Sen. Sally Harrell, who sponsored the legislation, but it's far from what is needed to eliminate the state's waiting list.

And without state money to increase how much agencies can pay employees, families won't be able to take advantage of the new waiver money because there won't be enough staff to serve them.

"You've got to put the waiver money out there and you've got to put the provider money out there," Harrell said.

AD

Kemp signed legislation, sponsored by Harrell, requiring regular evaluations of the rates for service providers and caregivers who in Georgia earn roughly $10 an hour, but it would take additional legislative action to meaningfully increase wages.

“That’s less than a babysitter, less than a dog walker, less than a grocery clerk,” said Philip Woody, a disability advocate in Georgia, who worked with Harrell. “That’s just ridiculous.”

‘It’s still a huge problem’

Waiting lists for services exist because states, through their Medicaid programs, can cap the number of slots available for people with needs. People with intellectual and developmental disabilities typically spend years on a waiting list, according to the Kaiser Family Foundation, and it’s not uncommon for a person to spend a decade waiting for a spot to open up, said Wilush.

And even when states like Georgia devote more money to open new slots, it may not be enough to recruit and retain the nurses and other direct support staff needed to care for people who have been approved for services, leaving families in a tortured limbo in which they find themselves approved for services but unable to find anyone to do the work.

“You get off a waiting list for waivers and onto a new waiting list for services,” Woody said. His son Evan, who suffered a traumatic brain injury when he was 18 months old, qualifies for services but waited two years to get into a day program because there wasn’t enough staff.

In Oklahoma, the legislature put more than $21 million into the recently passed budget to clear the state’s 5,000-plus person waiting list, on which people wait up to 13 years.

AD

But even if the state manages to work its way through the waitlist — and some still feel it hasn’t provided nearly enough funding to do so — those approved for services may discover no caregiver is available to help them.

“It’s still a huge problem,” said RoseAnn Duplan, a policy and communications specialist with the Disability Law Center in Oklahoma. “We have people now qualifying for services, and when they go to find a provider, they are put on a waiting list for providers because there is just no staff.”

Oklahoma’s budget also included a 25 percent increase in provider rates set to take effect on Oct. 1, which will provide a boost but won’t be enough to compete

with retail or service work.

Costco or 7-Eleven pay $15 an hour, Duplan said, significantly more than what most agencies offer.

“Providers are a little bit panicked,” she said. “The pool of employees has dwindled because of wages going up in other sectors.”

Mary Ogle, chief executive officer at A New Leaf, a nonprofit in Oklahoma, said she recently completed 62 units of affordable housing for people with intellectual and developmental disabilities. Those rooms sit empty because she cannot find staff.

Dozens of families are left waiting. Some parents in their 80s thought the housing would answer their prayers.

“It’s crushing,” Ogle said. “We did everything right; we built additional housing for this population because, across the country, there is a huge shortage, so, we as a provider, said, ‘We will fix that.’”

AD

Oklahoma’s unemployment rate is 2.9 percent. The job market is so hot that people who interview in the morning have often accepted another offer by the afternoon, Ogle said.

She offers a starting rate of $11.73 an hour, which can go to $15.73 with overtime. But Hobby Lobby, the popular retail chain, pays $18.50 an hour.

Ogle has a list of 150 people waiting for residential services, the kind she could fill if she could staff the 62 waiting units.

“I’ve never had a waiting list before,” she said. “Our waiting list has continued to grow because we don’t have the staff to add more people.”

FILED UNDER: DISABILITIES, AMERICANS WITH DISABILITIES ACT, HOME CARE,

Huddle
A play-by-play preview of the day's congressional news

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APPENDIX B

NOW & COMP Waiver Entry Process

Georgia Department of Behavioral Health & Developmental Disabilities

1

Application: An individual or individual's representative completes and submits an application online or at the nearest DBHDD regional office.

2

Pre-Eligibility: DBHDD staff review the application and all relevant materials. The individual's pre-eligibility is determined based on a psychologist's review of all the documentation (and at times a face-to-face interview).

3

Planning List: The State Planning List Administrator (PLA) contacts the individual shortly after being determined pre-eligible to discuss the process and complete screening. The PLA makes appropriate referrals for support, such as vocational rehabilitation, family support, etc.

4

Funding: The most appropriate source of funding for services is identified to meet the individual's needs. An individual may be recommended for the NOW or COMP waiver, as well as different state-funded programs.

5

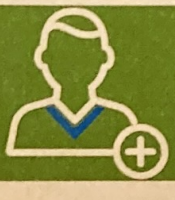
Waiver Eligibility: Individuals are reviewed by Alliant/Georgia Medical Care Foundation to determine level of care for eligibility for the NOW or COMP waiver.

6

Evaluations: Assessments are required to ensure that proper support of an individual's specific needs are met.

7

Individual Service Plan: The PLA, along with the individual and identified service providers, complete the first annual plan which identifies the goals and services based on the individual's strengths and assessed needs.

8 

Service Entry: The individual begins receiving services.

APPENDIX C

spadd

Service Providers Association for Developmental Disabilities

August

2022

DIRECT SUPPORT PROFESSIONAL WORKFORCE CRISIS

Key Statistics

Recent reports from ANCOR and United Cerebral Palsy illustrate the alarming consequences of the current DSP workforce crisis. These key findings mirror what SPADD member organizations are experiencing and reporting.

Key Findings: The Case for Inclusion 2022[5]

Nationally, the **average DSP turnover rate** in 2020 increased by about one percentage point to **43.6%**. **Georgia's** DSP turnover is **46.7%**.[3] Meanwhile **vacancy rates for full-time direct support positions** increased from 8.5% in 2019 to 12.3% in 2020 – a roughly **45% increase**.

As of 2018, **16 states** and the District of Columbia had **closed** their last remaining large, **state-run institutions**.

1 in 5 (21.1%) people with IDD who received **employment or day** supports were participating in an **integrated employment service**.

There are **589,940 people on states' waiting lists** for home and community-based services nationally. Nearly **4 in 5** (78%) of those waiting were **concentrated in just five states**. **Georgia's waiting list** has ballooned to **7,155** people.

Key Findings: The State of America's Direct Support Workforce 2021[2]

77% of community providers are **turning away new referrals**.

58% of community providers are **discontinuing programs and services**. This represents a 70.6% increase since the beginning of the pandemic.

84% of community providers are **delaying the launch** of new programs and services.

81% of community providers are **struggling to achieve quality standards**.

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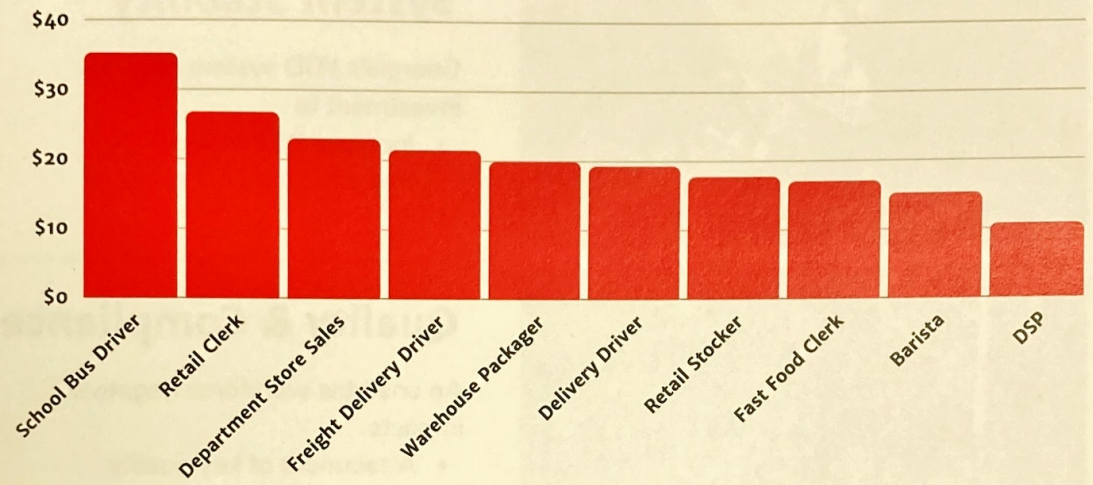
5. United Cerebral Palsy & ANCOR Foundation, "The Case for Inclusion 2022", June, 2022, https://caseforinclusion.org/application/files/1716/4658/7147/Case_for_Inclusion_2022_Blazing_Trails_to_Sustainability_for_Community_Disability_Services.pdf

Wage Discrepancy

Despite the life-changing work and impact DSPs provide to the wonderful people they serve, the rate of pay for DSPs hasn't increased with demand, inflation or the move away from institutionalizing individuals. These caregivers are integral in supporting individuals with disabilities to live successfully in their communities, avoid more costly institutional care and enable Georgia to comply with the integration mandate of the Americans with Disabilities Act. They are providing a highly valuable service that used to be fulfilled by government institutions, yet they still aren't making a living wage.

Competitors vs. DSP Hourly Wage

Georgia average wages per hour.[6]



70%

In Georgia, Direct Support Professionals earn an average of 70% less than school bus drivers.

What does a DSP job entail?

The job responsibilities of a DSP incorporate aspects of all these roles and professions:

- **Special Educator** - Teach social, financial, and vocational skills
- **Friend** - Be an active listener and shoulder to lean on
- **Record Keeper** - Document all services provided, medications, activities, food intake, and more
- **Therapist** - Assess needs, guide relationships and emotional health
- **Housekeeper** - Clean house, perform light maintenance, laundry
- **Coach** - Facilitate physical exercise and fitness routines
- **Nursing Assistant** - Physically assist with bathing, dressing, feeding, and toileting
- **Advocate** - Speak on someone's behalf to ensure their rights are respected and secured
- **Dietician** - Develop and follow meal plans, including specialized medical diets
- **Medication Technician** - Oversee and document administration of multiple medications per person
- **Driver** - Provide all transportation to community activities, jobs, family visits
- **Cook** - Prepare all daily meals
- **Case Manager** - Comply with local, state, and federal regulations for services

6. Indeed, "Salaries", August 17, 2022, https://www.indeed.com/career/salaries

Conclusion

In order to preserve Georgia's system of services for people with I/DD, reimbursement rates must be increased enough to provide a competitive wage for Direct Support Professionals.

System Stability

Georgia's I/DD system requires investment to

- Increase DSP wages
- Mitigate high DSP turnover

Quality & Compliance

An unstable workforce negatively impacts

- Attainment of key quality indicators
- Successful regulatory compliance

Health, Wellness, & Safety

DSPs provide critical support that leads to

- Improved health outcomes
- Safety through supervision

"The DSP crisis is extremely costly to the service system and to the individuals who need assistance. The DSP crisis puts people with I/DD who need assistance at great risk of harm, contributes to unreasonably long waiting lists for services, and is leading many people to reconsider more expensive institutional models of segregated care outside their home."

- Carol Britton Laws, Ph.D
Clinical Associate Professor at The University of Georgia

spadd

Service Providers Association
for Developmental Disabilities

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SPADD
DIRECT SUPPORT PROFESSIONAL
WORKFORCE CRISIS 2022

APPENDIX D

Heidi J. Moore- short bio

Parent advocate for individuals with disabilities and childhood cancer research.

Proud Mother to Jacob – 22 yrs. old with DS, Autism, and cancer survivor and Jared – 20 yrs. old at UAB studying medical sociology and looking at healthcare disparity in US.

Advocating for over 20 years at both local, state, and federal level. Have worked on various issues in GA including Katie Beckett/Deeming Waiver sliding scale, Medicaid healthcare, waivers, funding and recently COVID19 vaccination prioritization.

Advocacy distribution list of over 1200 members.

Moderates Four Facebook groups- including the NOW/COMP waiver group w/ over 600 members.

On various disability Boards including Adult Disability Medical Healthcare (ADMH) – the only healthcare medical home for individuals with DD aging out of pediatrics.

Currently , advises the DBHDD DD Advisory Council for almost 10 years.

Jacob has had the COMP waiver for over 16 years where we participant direct our services.

Senate Study Committee on People with Intellectual and Developmental Disabilities
August 24, 2022 - 11:00am at CAP 450

Concerns / Issues:

1. Difficulty in navigating disability services throughout the system.
2. Long waiting lists (over 7,000+ families waiting for NOW/COMP Waiver)
3. Switching to a Managed Care model for Medicaid healthcare for Aged Blind and Disabled (ABD) population is NOT the solution to funding waivers. Managed care has not worked in other states for our population! We would just be taking healthcare access & specialized services away from everyone who currently has ABD Medicaid who have higher needs.
4. Access to services when needed – crisis, aging out of high school (over 21 yrs), aging parents, etc.
5. Low funding rates for services that are provided. Need to be competitive.
6. Other issues: lack of flexibility to transfer funding within waiver system, computer technology has not been improved to help family access, etc.

Solutions:

1. Disability services is a bipartisan issue. It's a matter of priorities of taking care of those that can't take care of themselves in GA.
2. More communication for families utilizing disability services.
3. Transparency of services. Family friendly language.
4. Funding NOW/COMP waivers so more families have access to services in GA.
5. Flexibility for hiring family members for waiver services.
6. Transparency of all systems with one point of entry needed. (many of these solutions do not require funding – just better communication/systems be in place)

Heidi J. Moore- Parent Advocate for individuals with disabilities & childhood cancer research.
Proud Mom to Jacob – 22 yrs old with Down syndrome, Autism and Cancer Survivor

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Alpharetta, GA
8/24/22

APPENDIX E

GOTA

Georgia Occupational Therapy Association, Inc.

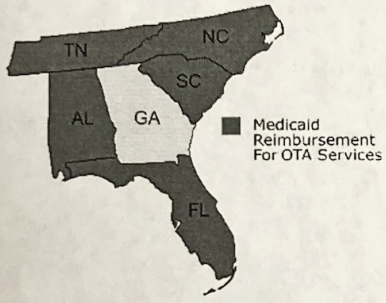
FACT SHEET

MEDICAID

The Need for Coverage of Services Provided by Occupational Therapy Assistants

In Georgia, 1.4 million children and 54% of children with special healthcare needs are covered by Medicaid. Many of these are served under the Children's Intervention Services (CIS) program, mostly in clinics, institutions, and home and community based settings. Despite occupational therapy (OT) service providers having waiting lists for children needing pediatric OT services, Georgia's Medicaid program does not cover these services provided by licensed Occupational Therapy Assistants (OTAs).

Local States Medicaid Reimbursement



All bordering states reimburse for OTA services under Medicaid.

In fact, nationally, 84% of the states do the same. CHAMPVA (Civilian Health and Medical Program of the Department of Veterans Affairs) and TRI-Care also pay for services provided by OTA level practitioners.

Georgia has several precedents for Medicaid reimbursement of providers who work in teams:

- Medicaid already covers OTA services to students with special needs in schools (CISS program). This includes working with OTs, physical therapists, and speech professionals.
- Georgia Medicaid covers physician assistant (PA) services. Similar to the case for OTAs, PAs are licensed providers with a scope of practice (with some restrictions) similar to that of the professional supervising them.
- Medicaid covers Applied Behavior Analysis (ABA) services to children under the Autism benefit. Most reimbursed ABA services are provided by registered technicians working for ABA licensees. By comparison to OTAs these technicians have far less training than an OTA (high school degree and a 40 hour online course with no or limited patient contact vs. an OTA's bachelors or associate degree, which includes field work).
- The Professional Licensing Board for Occupational Therapy has policy which regulates the ongoing professional development, and supervision of OTAs as a condition of state licensure.

Key Reasons to Support

- ❑ There is a healthcare work force shortage in Georgia; some CMOs have difficulty fielding an adequate network of providers, especially in rural areas.
- ❑ Pediatric therapy clinics throughout the state report difficulties recruiting OTs to fill vacant positions, and using OTAs is not feasible due to the lack of Medicaid coverage of their services.
- ❑ The shortage of therapy providers for children with disabilities is particularly harmful because delays in services increase a child's degree of developmental delay. The use of OTAs to provide treatment would free up occupational therapists to evaluate more children already referred for OT services.
- ❑ OTA academic curriculum trains OTAs to treat children receiving OT services. OTA faculty indicate that many of their graduates interested in pediatrics leave Georgia due to Medicaid restrictions.

For all of the above reasons, the Georgia Occupational Therapy Association (GOTA) respectfully requests the Georgia Department of Community Health conform its practices to prevailing health policy by initiating reimbursement of Medicaid services provided by Occupational Therapy Assistants.

Occupational Therapy Assistants & Georgia Medicaid

The Who, What, When, Where, How & Why OTAs are important team members

WHO are Occupational Therapy Assistants?

Occupational Therapy Assistants (OTAs) are nationally certified and state license regulated rehabilitation professionals who have completed an associate or bachelors degree level of college training in the field of occupational therapy. Just like Occupational therapists (OTs), OTAs must complete their college program and then demonstrate entry-level competency by successfully completing a nationally recognized entry level examination[1] and fulfill individual state requirements for licensure prior to working in the profession. These state licenses are then renewed biannually and require participation in continuing education as a condition of renewal. All occupational therapy practitioners in the state of Georgia are regulated by the Georgia State Board of Occupational Therapy, and governed by the general provisions of law and the Georgia State Board of Occupational Therapy Practice Act.

WHAT do Occupational Therapy Assistants do?

OTAs use their knowledge to provide services for habilitation, rehabilitation, and promotion of health and wellness for clients with disability and non-disability related needs[1] through the provision of services that address goals outlined on the treatment plan. The treatment plan is typically developed during an evaluation completed by an OT. This OT then oversees the treatment plan and supervises an OTA assigned to carry out the plan. OTAs use their unique training to implement, deliver and modify treatment interventions that address the goals contained in the treatment plan. This includes focus on areas such as daily living activities, leisure activities, school, work, and play. OTAs are also trained to provide education and training to support caregivers/family members in the care of the client.

WHEN do Occupational Therapy Assistants Work with Clients?

OTAs receive training on human performance from birth to death and can provide treatment interventions to all ages. OTAs work in the same types of settings as OTs. OTA training focuses specifically on skills needed to understand a treatment plan and create and deliver occupational therapy interventions. In fact, many of the academic standards related to treatment intervention are the same for both OT and OTA education programs. OTs, on the other hand, receive a significant amount of training focused on the evaluation process including developing the treatment plan.

WHERE do Occupational Therapy Assistants Work?

The scope of practice for OTAs includes providing interventions to all age ranges along the continuum of services (institutional, outpatient, home and community settings, research facilities[1]). OTAs have the knowledge, skills, and abilities to treat clients in the 0-18 population, and are able to do so in home, medical, and community settings including early intervention, outpatient clinics, inpatient hospitals, and schools with oversight from an OT. OTAs in surrounding states are actively involved in the treatment of babies and children in these types of settings.

HOW are OTAs Supervised in Georgia?

OTAs are governed by the AOTA Scope of Practice[1], the State Board of Occupational Therapy Rules and Regulations, as well as regulations implemented by reimbursement sources.

O.C.G.A.§43–28–3 Definitions (8): "Occupational therapy assistant" means a person licensed to assist the occupational therapist in the practice of occupational therapy under the supervision of or with the consultation of the licensed occupational therapist and whose license is in good standing.

Rules and Regulations of the State of Georgia Department 671, Chapter 671–2, DEFINITIONS Rule 671-2-.02: *Supervision Defined*: Supervision as used in the law shall mean personal involvement of the licensed occupational therapist in the supervisee's professional experience which includes evaluation of his or her performance. Further, supervision shall mean personal supervision with weekly verbal contact and consultation, monthly review of patient care documentation, and specific delineation of tasks and

1. American Occupational Therapy Association. (2021). Occupational therapy scope of practice. American Journal of Occupational Therapy, 75(Suppl. 3), 7513410030. https://doi.org/10.5014/ajot.2021.75S3005