APPENDIX

Senate Legislative Oversight Committee
Wednesday, June 10, 2015
10:00 AM in Committee Room 4, 1st floor Annex
Testimony by Dawn Apgar

Chairman Gordon, members of the Senate Legislative Oversight Committee, my name is Dawn Apgar and I'm a Deputy Commissioner with the NJ Department of Human Services responsible for overseeing the Division of Developmental Disabilities – of which Liz Shea, to my right – is the Assistant Commissioner.

We're here today to share information about the State Transition Plan, Return Home New Jersey and the shift to Fee for Service provider payments. I want to thank you for accommodating our schedules today and I'm hopeful our attendance will bring a clearer understanding of these initiatives to the committee.

As we have discussed previously, and most recently at our Senate budget hearing, changes are happening nationally with regard to services for people with developmental disabilities.

Before the late 1970s, developmental centers were the only option for individuals with developmental disabilities, who could no longer live with family members. By 1977, more than 7,600 people lived in developmental centers in New Jersey. However, as community programs expanded, New Jersey saw a <u>dramatic</u> decline in census, and in the 1990s, the State closed two developmental centers. Also, as you are aware, with the continued decline in census, the State closed two additional developmental centers this past fiscal year. The census, statewide now is about 1,600 and declining.

As codified by the 1999 Supreme Court Olmstead decision, people with intellectual and developmental disabilities have the right to live in the community and to enjoy the experiences that enrich all of our lives. This decision is supported by the US Department of Health and Human Services' Office of Civil Rights as well as the Americans with Disabilities Act.

Based upon the Olmstead decision, many best practices have been identified and culminated in the US Department of Health and Human Services' Home and Community Based Services' final rule, which was issued in March of 2014. The Rule requires all states to revise how they provide Medicaid home and community based services to seniors and people with disabilities. In order to comply, every state, including NJ, had to develop a proposed plan that it will follow in order to meet the federal requirements by 2019.

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The draft Plan produced strong emotional and operations-based support for, and opposition to, various provisions. Over 1,000 comments were received in the form of letters, phone calls and testimony at the two public forums. The process successfully opened up an important dialogue that resulted in some very constructive and useful input, which was included in the revised Plan.

I know that this committee also is interested in Return Home New Jersey, which began in State Fiscal Year 2009, when nearly 700 adult NJ residents with developmental disabilities were receiving residential services in out-of-state, congregate care facilities. The state's inability to receive a federal match on these services – in conjunction with significant uncertainties about our ability to adequately monitor the care and wellbeing of individuals in out-of-state programs, – has long been a concern. The ability to receive federal funding allows the division to serve more eligible individuals with developmental disabilities. And with regard to proper oversight, notably, New Jersey is not alone among states that have these issues related to monitoring.

In fact, those issues were primary among the very concerns that led to the passage of Billy's Law in New Jersey in 2008. We're aware of circumstances in other states where the federal Department of Justice and Disability Rights Organizations have stepped in and questioned the care provided in some of the out-of-state facilities.

With this in mind, New Jersey has concentrated on returning out-of-state NJ residents to in-state placements in order to more closely monitor their care and safety – as well as to bring them into a network of care that often is closer to their families.

Since 2009, the Division of Developmental Disabilities has carefully and successfully moved 170 people who were living in out-of-state placements to New Jersey, but there still are 371 individuals remaining out-of-state. Some of these relocations take quite a long time. We spend an extraordinary amount of time finding the right agency, the right location and the right setting to ensure that the transition works for the consumer. It is worth mentioning that one of the challenges with this initiative is that some individuals have been out of state for many years and families are understandably concerned about relocating their loved one.

The circumstances for each individual are different and are based upon each individual's support needs. These moves take time, with many relocations taking years to ensure appropriate transitions occur and services are in place.

The foundation of this effort is the many private community provider agencies in our state that support the needs of individuals with significant intellectual and developmental disabilities, each and every day. The Division works with more than 280 provider agencies that provide quality services and supports in community settings – which exist statewide. DDD supports nearly 30,000 individuals, including people with very complex needs such as 24-hour nursing and behavioral supports. There are over 10,000 being served in group homes and other similar settings across New Jersey.

This community expansion has resulted in many more resources and supports for individuals to live in New Jersey communities, and opportunities for those returning to New Jersey, which did not exist previously. In fact, since FY 2010, more than $350 million in state and federal funds have been invested in home and community based programs and services. All of that money – excluding that which is spent on out-of-state services – is matched with federal funds.

Over the last two fiscal years, the Division of Developmental Disabilities opened about 1200 new beds in community residences. These provider agencies have expanded our New Jersey service system to local communities throughout our state, and through their efforts, today people with developmental disabilities are no longer segregated from community life because of their disabilities and the care associated with them.

With regard to safety and appropriate oversight, New Jersey's residential programs are extensively monitored to ensure that community homes are well run and well maintained, and provide residents with the services they need to live safely and successfully in the community. All must adhere to strict licensing requirements.

The Department's Office of Program Integrity and Accountability monitors agency-run community homes and performs annual inspections, through unannounced visits, or if complaints or concerns are raised. Every incident that results in an injury, neglect, exploitation or death is investigated by the provider agency, the Department's Office of Investigations, and local or state police, as appropriate.

In addition, the New Jersey Central Registry of Offenders against people with developmental disabilities, which was passed by the legislature and signed into law in 2010, prohibits the potential rehiring of an offender by another DDD service provider. This also prevents potential harm.

We're working with families every day to show them that the system of care has dramatically changed over the last several years. Many more residential and program options are available than there were when their child was moved out-of-state. Many more rules and regulations regarding treatment and care have been implemented and enforced.

Lastly, I understand the committee is interested in learning more about the Division of Developmental Disabilities' shift to fee-for-service reimbursement. For the last several decades, the Division of Developmental Disabilities has been built on a cost reimbursement contracting model. This model funds division services through a network of third party providers by contracting for capacity and then applying a cost reconciliation process after the close of the contract. In the current model, the Division is the Medicaid provider of record and performs a weekly claiming to the federal government to access the available federal match.

In accordance with the submission of the Comprehensive Medicaid Waiver to the federal government in late 2011, the Division began working to shift to a Medicaid-based fee-for-service

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model of payment. In early 2012, the Division began meeting regularly with providers and families to discuss this shift, solicit their input, and plan for the change. In March of 2013, the Division entered into a formal rate setting process with a national rate setting firm for the express purpose to develop standard rates for the 26 services that the division will fund in this new model. The rate setting process included advisory committees made up of providers, individuals with disabilities and their families, and lasted approximately 18 months. The draft rate sheet was made publicly available in July of 2014, and since that time, the division has worked closely with the provider community to ensure an adequate network of service providers are able to operate in the new system.

This shift to a fee-for-service model will provide many benefits. First, the current model is less efficient as services are paid for prior to service delivery and funding amounts vary depending on initiative and date of entrance into the system. The new system will allow us to pay for services after they are delivered, thus ensuring the State does not pay for unused capacity, and will provide standard rates across the entire service delivery system to provide for a more equitable model. Second, each service provider will be a Medicaid provider who will directly bill under a prior authorization process. But perhaps most importantly, this shift will allow new providers to enter the system, thereby creating a great deal more choice for individuals and families, and will also provide all consumers with individualized budgets and an enhanced ability to self-direct their services.

The shift into this new fee for service model is expected to begin this July and gradually over the course of the next 18 months. The division is working with the provider community to finalize the details of our plan to provide bridge funding to assist our current providers with cash flow needs during the transition, as we believe that will be critical to the success of the transition. In terms of stakeholder involvement, the Division has recorded over a dozen webinars for stakeholders over the course of the past year, and key members of the Division's management team have conducted over 175 presentations to providers, individuals with disabilities, and their families over the past three years in preparation for this shift. The Assistant Commissioner and her management team also have regular monthly meetings with providers and families to ensure appropriate input.

I hope you have found this overview helpful, we are happy to answer your questions.

PARLESREKEM LLP
ATTORNEYS AT LAW
675 MORRIS AVENUE, SUITE 200
SPRINGFIELD, NEW JERSEY 07081
PHONE: 973-564-0055
FAX: 973-544-9616
WWW.PARLESREKEM.COM

Testimony of Lisa McCauley Parles, Esq.
New Jersey State Senate
Legislative Oversight Committee
June 10, 2015

Good Morning. Thank you for inviting me to speak about this critical issue. My name is Lisa McCauley Parles. I am a partner in Parles Rekem, a law firm representing individuals with disabilities and their families. I am also the mother of a 24 year old young man with autism and have several concerns regarding the limited options for individuals with challenging behaviors offered under New Jersey's proposed plan. The revised plan, which is more restrictive than the federal regulations, will serve to limit options for the disabled and in many circumstances could endanger the lives and health of our most vulnerable citizens.

There remains a great deal of confusion about what the revised plan does, and does not, do and what is and is not required under the federal rule. The Plan continues to limit choices. Under the Plan, going forward, DDD will only fund a 4-6 person group home or set-aside units in a development where no more than 25% of the residents are disabled. In addition the plan prohibits settings where the participants' home and vocational programs are located on the same property. This is known as the ban on co-located programs. While only DDD can only definitively answer the question of what they will require going forward it appears that there will not be funding available for programs that are farmsteads, intentional communities or campus based programs. Why is there so much confusion about what the Plan mandates? One of the reasons is that rather than clearly state the 4-6 bed limit or the 25% density restriction the revised plan pointed to 2 federal programs: the money follows the person and the HUD 811 neither or which dictates states' plans for adult services.

The initial plan was revised and when it was, there was great relief that people would not have to move from their residential settings. However, it has proven difficult to get answers from DDD on whether existing co-located programs will continue to be funded. It is important to note that a significant percentage of the DD/ID population need campus based programs in order to be safe.

My son, Andrew, currently lives on Bancroft's Lakeside Campus which provides him with appropriate support and supervision. At Lakeside, the presence of on-site behaviorists is a key component as is the ability to remain productive on days that his behaviors make it impossible to go to a job site in the community. In addition, in a campus setting if a crisis occurs the response time of additional staff is significantly shorter than in a group home. His campus is not an institution and his experience there on many days is much more inclusive than life in a group home. Under the state's proposed plan it is still unclear and unsettled if this outstanding program that serves 48 individuals with severe and challenging behaviors will be forced to change a successful, clinical model.

On many days Andrew does participate in a number of community based projects such as Meals on Wheels. However, in addition to working on these meaningful projects, Andrew has tragically:

- gone 3 days without sleeping;
- gone 6 days without eating;
- lost 100 pounds in three months; and
- suffered a self-inflicted traumatic cataract.

More recently, he detached retinas in both eyes due to self-injury and had to undergo two separate surgeries. Andrew was not successful in a community group home. It also was not an experience that led to more community integration. For all practical purposes, the only interaction the residents had with neighbors was when they complained that the music therapist was too loud. The notion that simply placing individuals in group homes leads to an inclusive experience is a fiction. There are many "Andrews" out there whose needs cannot be

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met in apartment settings or community group homes. In order to keep individuals with severe and challenging behaviors safe, co-located programs must be permitted. In fact, given the need more must be built.

The federal rule allows for campus settings and settings where individuals live and work in the same location. In a December 3, 2014 letter, CMS Director Barbara Coulter Edwards stated "It is important to note that the regulation does not prohibit site specific settings..." Criteria set by CMS are not based on physical characteristics or density. All regulation and licensing characteristics should be based on outcome oriented criteria and the individual's experience.

Given the continued confusion about what the federal rule requires, I asked the Coalition for Community Choice to review New Jersey's plan. Yesterday I received a letter from the Coalition in which its National Coordinator states that the Plan "includes more stringent criteria than the federal regulations require and are based on physical characteristics. "

CCC also pointed out that New Jersey has unnecessarily relied on restrictions from two federal programs in crafting its Plan. The Money Follows the Person program which is a federal finance incentive designed to assist people at risk of institutionalization has a 4-6 bed limitation. However, this federal program in no way mandates statewide housing policy. Neither does HUD Section 811 which is also in the Plan.

According to CCC, the bed limitation is not mandated by the federal rules and it may, in fact, be detrimental for states to overly rely upon one type of setting. Moreover, CCC explained that although HUD 811 contains a density limit of 25%, there are many funding sources for affordable housing that do not have this requirement. These restrictions have no place in the plan and serve only to limit choice and stunt future development of the type of programs that are desperately needed in New Jersey.

DHS ignored the revisions requested by stakeholders. Rather than clearly stating the bed limit or density restrictions, in wily fashion, DHS rewrote the plan in a way that kept these discriminatory restrictions and by citing other federal programs caused confusion.

A number of New Jersey residents have filed objections to the STP with CMS based upon the State's failure to make changes that were requested by the majority of stakeholders. In addition, New Jersey's citizens have objected to DDD's misleading reliance on the Money Follow the Person and HUD 811 programs. They also based their objections on the lack of transparency in the process. The initial proposed plan was released by DHS late in the day on January 26, 2015. There were only two public comment sessions each of which was two hours long. Remarkably, the first of two public comment sessions was scheduled for 10:00 a.m. the very next morning! At the second public comment session, testimony was limited to three minutes per person and speakers were cut off, even if they had not finished their statements. Approximately eighty people present wished to testify but the session ended, promptly after two hours, with only 36 having been given the opportunity to have their voices heard. At that point, despite the pleas and protestations of the audience members, DHS officials walked out of the hearing room to the dismay of the stakeholders present. The unnecessary and untoward limitation of public comment was distasteful and disrespectful. Other states provided far more opportunity for public comment and stakeholder involvement.

Throughout the entirety of the process, New Jersey DHS engaged in conduct that was anything but transparent or cooperative. Unlike many other states, New Jersey released its proposed plan at the 11th hour and left little time for constructive evaluation or revision. Many states began the STP process as early as January of 2014 and issued multiple revisions of their plans allowing for review and discussion by stakeholders. Similarly, other states provided far more opportunity for public comment than did New Jersey. For example, Wyoming which is the least populated state in the US and has a total population of 563,000 people which is less than the population of NJ's Ocean County held 8 public input sessions.

In addition, New Jersey has failed to establish the type of cooperative process that exists in other states where state government, families, providers and persons served have collaborated with a goal of expanding housing options. For example, Florida has awarded almost $50 million in tax credits to invest in the development of accessible and affordable

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housing mandating that 80% of the units be for individuals with developmental and intellectual disabilities. In Ohio, fourteen members of the state's congressional delegation including the Speaker of the House recently sent a letter to U.S. Secretary of Health and Human Services in support of farm communities where residents live and work at the same location.

In addition to the right of integration, our disabled citizens also have the right to be adequately supported in programs that meet their actual needs, to be presented with options and most importantly to be safe. To those who say that all campus based programs should be barred, I ask the following: if other citizens may choose among options such as living in an over-55 community, or on a college campus why should the disabled not have the option of living within a campus community that keeps them safe and appropriately meets their needs?

New Jersey's plan must be rejected.

CCC
Coalition for Community Choice *Increasing options. Decreasing barriers.*

June 9, 2015

Lisa Parles, Esq.
Parles Rekem LLP
675 Morris Avenue, Suite 200
Springfield, New Jersey 07081

RE: Request for Technical Assistance from the Coalition for Community Choice

Dear Ms. Parles:

Thank you for your inquiry regarding requirements of Money Follows the Person (MFP) and HUD Section 811 PRA required use within the New Jersey State Transition Plan, as well as restrictions on settings with co-located programming. As requested:

Money Follows the Person (MFP)[1] is a federal financial incentive, which is designed to encourage states to move individuals with intellectual/developmental disabilities (I/DD) or for those at risk of institutionalization to Home and Community-Based settings. The 4/6 bed limitation requirement of the MFP incentive is not mandated for other settings where Home and Community-Based Services (HCBS) waiver funding may be used. According to our research, it may be detrimental for states to construct policy for a specific funding incentive thereby over-relying on one type of setting.

The HUD Section 811 Supportive Housing for Persons with Disabilities program[2] provides funding to develop and subsidize rental housing with the availability of supportive services specifically for very low- and extremely low-income adults with disabilities. The required density limitation of 25% of units set aside for those with disabilities is applicable specifically to this HUD program. Other affordable housing development funds do not include this requirement.

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[1] http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/balancing/money-follows-the-person.html

[2] http://portal.hud.gov/hudportal/HUD?src=/program_offices/housing/mfh/progdesc/disab811

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CMS Guidance[3] examines settings that may have the effect of isolating individuals with disabilities and identifies "co-located and operationally related" settings as one of four different examples of how a setting may isolate individuals with disabilities. If these settings meet the federal requirements for HCBS settings, they are permitted.
The federal regulations describing the requirements for HCBS settings[4] intentionally exclude descriptors based on physical characteristics of settings and instead use outcome-oriented criteria. The CMS HCBS Settings Fact Sheet includes the following statement:

> *In this final rule, CMS is moving away from defining home and community-based settings by "what they are not," and toward defining them by the nature and quality of individuals' experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics.*[5] *(italics added)*

New Jersey State Transition Plan includes more stringent criteria than the federal regulations require and are based on physical characteristics. Institutional attitudes and abuse can occur in any setting, therefore it is imperative that states continue to use outcome-oriented criteria for determining eligible HCBS settings and not rely on criteria based on physical characteristics.

Please do not hesitate to contact me with further questions or clarifications.

Sincerely,

Desiree Kameka
National Coordinator

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[3] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf
[4] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Requirements-for-Home-and-Community-Settings.pdf
[5] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/HCBS-setting-fact-sheet.pdf

Autism™
NEW JERSEY

500 Horizon Drive
Suite 530
Robbinsville, NJ 08691

800.4.AUTISM
609.588.8200
609.588.8858 (fax)

www.autismnj.org

Testimony on DHS/DDD Statewide Transition Plan for HCBS

Senate Legislative Oversight Committee Hearing
June 10, 2015

Chairman Gordon, Vice Chair Weinberg, and committee members, thank you for the invitation to appear before you this morning.

Autism New Jersey strongly commends the Department for their substantial efforts to bring New Jersey in compliance with the CMS Final Rule on Home and Community-based Settings (HCBS) as articulated in the Statewide Transition Plan. It is fundamentally a good plan that, as we all know, raised some questions and concerns from the community. Autism New Jersey is appreciative that the Department amended their draft plan based upon community input.

For example, the Department clarified that it will continue to support the development of new group homes that comply with the HCBS Final Rule and Department policies. The Department also incorporated the community's feedback on the following concerns:

- More flexible requirements for community integration within day programs
- Site-specific remediation plans for existing residential settings to be determined compliant with the HCBS Final Rule
- A waiver of policy prohibiting co-location of services when specific clinical reasons are provided and included in the Person-Centered Plan

In our view, there is only one remaining concern: the size and density restrictions on new housing. The community's perspective is clear: provide us with a codified appeal process through which settings that exceed the quantitative limits can be evaluated. There are some settings that exemplify the fundamental principles of the HCBS Final Rule and its focus on choice, individuals' experiences, and outcome-oriented criteria. The community needs as many options as possible and numbers alone should not be an obstacle to finding someone a home they so desperately need.

We all know families who need or want something more or different than the settings allowed under the proposed rules. With more than 26,000 individuals with I/DD living with a caregiver over the age of 60 in New Jersey, now is the time to increase all housing options.

It is our position that every plausible type of community-based housing option should be considered before it is excluded. These policies should not limit housing choices. Ideally, these policies would provide the processes by which a range of community-based choices can be made in the individual's best interest.

We look forward to continuing our dialogue with the Department to develop policies that do not unnecessarily restrict housing options.

Thank you for the opportunity to provide these comments. We look forward to our collective dialogue to meet the needs of individuals with autism.

Sincerely,

Suzanne Buchanan

Suzanne Buchanan, Psy.D., BCBA-D
Executive Director

Autism™ NEW JERSEY

DHS/DDD Statewide Transition Plan – Status Report

The summary below is our preliminary analysis of the final plan issued on April 17, 2015. Please check back for updated content. This document follows the framework of the DHS document, "STP Issues of Note." Blue text denotes DHS language from Final Plan.

Draft Plan Issue	Autism New Jersey Recommendation	Revised Plan Language	Policy Objective
1) Increase community-based living arrangements - The draft plan stated DHS' commitment to increasing community-based options through capital financing and funding for related costs.	Fully supported.	N/A (p.16)	N/A
2) Day Activities - The draft plan stated that recipients of HCBS must spend 75% of their day activities *in the community* in settings with people who are not recipients of HCBS.	Given the draft STP's 75% mandate, the community was understandably concerned that this rule was not in the best interest of some individuals. Thus, Autism New Jersey recommended the removal of the percentage in favor of a policy that would offer more flexible ways to meet community integration goals in a manner consistent with individuals' person-centered plans.	"The revised STP requires that individuals in day programs spend the majority of their time engaging in integrated activities with the broader community of non-HCBS recipients inside and/or outside of the day facility. DHS will work with the contracted provider agencies to develop policies and protocols in this regard. Further, the STP was revised to reflect that certification of day programs will include the review of plans from day providers to demonstrate how meaningful community engagement will be provided." (p. 17-18)	Achieved

3) Congregate Residential Settings - Existing - The draft plan was silent.	Given the draft STP's mandated compliance with 4-person limit (6 with special approval) for new congregate settings, the community was understandably concerned that the plan's silence on existing settings may result in some individuals being displaced. Thus, consistent with the CMS Final Rule, Autism New Jersey recommended the development of a written policy that included stakeholder input to assess the individuals' experiences and outcomes rather than relying solely on numbers.	"The revised plan clarifies that all existing settings will be assessed by DHS for compliance with the HCBS Final Rule. If it is determined that an existing site is not compliant, the department will work with the agency/housing providers and residents to develop site-specific remediation plans. For existing settings, *the size of the site, in and of itself, will not be the sole determinant of compliance* with the Final Rule. Based on DHS' preliminary assessment of existing sites, 99% of residents will not experience displacement." (p. 14) (See footnote for #3)	Achieved
4) Congregate Residential Settings - Future - The draft plan indicated that new congregate residential settings will have a service level of four (4) recipients and may be expanded to six (6) where medical care is provided.	Given the draft STP's mandated compliance with 4-person limit (6 with special approval) per group home, the community was understandably concerned that <u>future housing development and options would be limited without regard for the community-based experiences</u> some of these housing options can afford. Thus, consistent with the CMS Final Rule, Autism New Jersey recommended the heightened scrutiny process as codified by CMS. This CMS-approved process or a NJ-specific DHS-approved process would have provided a written policy on how such settings can apply for consideration as community-based. This recommendation was based on the high and growing volume of individuals in need of housing and residential services in an effort to make available the fullest range of options to provide true choice and address clinical needs.	"The STP was revised to clarify that the development of any new congregate housing settings will need to comply with the guidelines on group home size contained in the federal Money Follows the Person Demonstration Program. However, NJ will allow group homes with a service level up to 50% higher than the standard in the federal MFP program in homes where medical care is provided, with prior approval from DHS. These guidelines align with DDD's current practice and the HCBS Final Rule. The STP also clarifies that the provision applies to new settings only and will not be applied retroactively to existing settings." (p. 14) *Note: 50% higher than the 4-person limit is a 6-person limit.*	Continued advocacy needed

5) Non-Congregate Residential Setting Capacity - The draft plan stated that in new settings where more than 4 residents are served, no more than 25% of the units could be specifically set aside for individuals with disabilities.	Given the draft STP's mandated compliance with a limit of 25% density, the community was understandably concerned that future housing development and options would be limited without regard for the community-based experiences some of these housing options can afford. Thus, consistent with the CMS Final Rule, Autism New Jersey recommended the heightened scrutiny process as codified by CMS. This CMS-approved process or a NJ-specific DHS-approved process would have provided a written policy on how such settings can apply for consideration as community-based. This recommendation was based on the high and growing volume of individuals in need of housing and residential services in an effort to make available the fullest range of options to provide true choice and address clinical needs.	"The revised STP clarifies that the provisions will apply to new settings, only, and not be applied retroactively to existing settings." (p. 14-15) (See footnote for #5)	Continued advocacy needed
6) Farmsteads - Farmsteads are seen as included in the provisions around residential settings that have the effect of isolating people receiving HCBS from the greater community.	Given the draft STP's exclusion of farmsteads and other 'settings that tend to isolate' according to CMS, Autism New Jersey recommended the heightened scrutiny process as codified by CMS. This CMS-approved process or a NJ-specific DHS-approved process would have provided a written policy on how such settings can apply for consideration as community-based. This recommendation was based on the high and growing volume of individuals in need of housing and residential services in an effort to provide the fullest range of options to address choices and clinical needs.	"The revised STP states that when considering any new development, DHS will consider proposals for settings that comport with the HCBS final rule and with any other applicable state and federal regulations." (p. 32)	To be determined - DHS' consideration of such proposals is encouraging. Such applications may include person or density numbers that exceed limits described above. We look forward to working with DHS to develop written policy that does not unnecessarily restrict housing options.

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7) Co-location of services - The draft plan stated that co-location of services (e.g., residential and day services, residential and self-directed services) was prohibited and programs needed to be compliant by July 1, 2016.	Given the draft STP's prohibition on co-location of services, the community was understandably concerned that this rule was not in the best interest of some individuals. Thus, Autism New Jersey recommended that this text be replaced with a policy that would offer more flexibility consistent with individuals' person-centered plans.	"The DHS will comply with all components of the Final Rule, which includes the ability for an individual to request a waiver of policy for specific clinical reasons, subject to inclusion in the person-centered plan, review by the DHS, and regular review of the waiver to ensure the restriction is still required." (p. 37) DHS extended the deadline for transition of day programs co-located with residential settings from July 1, 2016 to June 30, 2017 (p. 18) DHS clarified that individuals may work and or pursue entrepreneurial activities at home (p. 18)	Achieved
8) Implied Moratorium on Group Homes - The draft plan emphasized the current overreliance on group homes. "The existing portfolio of licensed group home beds will remain available to serve individuals who need and select that choice, while the direction of these incentives will increase the opportunities available for individuals who select other options."	Given the incentives for diversification of housing types and the current high percentage of group homes among available housing options, the community was understandably concerned that the development of group homes would be suppressed in favor of more independent living arrangements. Autism New Jersey recommended an increase in all types of housing options. This recommendation was based on the high and growing volume of individuals in need of housing and residential services in an effort to provide the fullest range of options to address choices and clinical needs.	"The DHS will continue to support with operating and service funding the development of new group homes that comply with the HCBS Final Rule and with DHS policies." (p. 16)	Clarified

Footnotes

Blue text denotes DHS language from Final Plan

#3 - Congregate Residential Settings - Existing

1) "DHS has revised the STP to note that the stakeholders will be provided the opportunity to review and provide feedback on the assessment tool before DDD conducts site assessments. DHS will consider all suggestions for inclusion in the site assessment tools. DHS has also revised the STP to explicitly state that individuals will be surveyed on their experiences in the STP and will be included in the site-specific assessments, in order to ensure that the experiences of HCBS recipients are reflected." (p.29)

2) "The state also wants to clarify that the site-specific tool uses exploratory questions provided by CMS in its guidance. The guidance was created to assist states in assessing whether the characteristics of HCBS, as required under the new rule, are present. While the tool mainly focuses on HCBS settings, a portion also looks at person-centered planning and whether the setting takes into account an individual's needs and choices in a way that maximizes his/her independence and ability to engage in the self-direction of services." (p. 29)

3) "In order to meet compliance with the CMS guidance for integration with the community, the DDD will consider adjusting its policies or regulatory requirements for existing housing to ensure that the settings prevent the isolation of individuals receiving HCBS from individuals not receiving those services in the broader community." (p. 15)

4) Assessment by DHS to be Conducted of HCBS Settings Licensed under NJAC 10:44A, NJAC 10:44B and NJAC 10:44C - April to July 2015 (p. 23)

#5 - Non-Congregate Residential Setting Capacity

1) "DDD has adopted a policy requiring all *new* integrated (non-congregate) settings align with the definition of integrated housing contained in the current federal U.S. Department of Housing and Urban Development (HUD) 811 Project-Based Rental Assistance (PRA) Demonstration program. These guidelines align with the HCBS Final Rule. These policies will cover both licensed settings and unlicensed, independent residential settings where individuals receive HCBS services through the CCW or the Supports Program. (Please note that private residential homes where individuals own their own homes, or where they live with a family member, are not governed by these policies." (p. 15)

Helpful Links

Final Statewide Transition Plan
Statewide Transition Plan Appendix B: Compliance Demonstration Crosswalks
Statewide Transition Plan Revisions Reference Chart

DHS website for Statewide Transition Plan content
Draft Statewide Transition Plan

The Arc.
of New Jersey

Achieve with us.

Robert Hage, President
Thomas Baffuto, Executive Director
985 Livingston Avenue
North Brunswick, NJ 08902
T 732.246.2525
F 732.214.1834
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Testimony before the Senate Legislative Oversight Committee
Executive Director Thomas Baffuto, The Arc of New Jersey
June 10, 2015

Good Morning. My name is Tom Baffuto and I am the Executive Director at The Arc of New Jersey. The Arc of New Jersey is the largest statewide advocacy organization for individuals with intellectual and developmental disabilities (I/DD) and their families. We have 20 affiliated local chapters providing services in all 21 counties in New Jersey. Our mission is to enhance the quality of life of children and adults with intellectual and developmental disabilities (I/DD) and their families through advocacy, empowerment, education and prevention.

I want to thank Senator Gordon and the Committee members for holding today's hearing as it brings attention to a number of critical issues that will have long lasting impacts on individuals with intellectual and developmental disabilities and their families for years to come. I appreciate the opportunity to talk with you about a number of the monumental policy decisions being put forward by the Department of Human Services and the corresponding changes individuals, families and providers are undergoing in order to prepare for the significant effects.

The service delivery system's shift to fee-for-service and the Home and Community Based Services Transition Plan will not only change the way individuals with I/DD live in the community, but also the way providers operate their businesses and the way families navigate the system. The Arc of New Jersey believes that some of the proposed changes may ultimately lead to a better system and we thank the State for their efforts to make improvements. However, for the changeover to be successful, it cannot be done hastily and should always include input from stakeholders.

In the last few years, the Department of Human Services has taken on many significant changes impacting people with intellectual and developmental disabilities. This many alterations, in such a short period of time, have caused a great deal of anxiety and trepidation for all involved. In addition to fee-for-service and the Home and Community Based Services Transition Plan, the Department closed two developmental centers; eligibility criteria changed and having Medicaid is now a requirement to receive services from the state; they are standing up the Supports Program (a new Medicaid waiver) and moving forward on Return Home New Jersey. While we agree philosophically with some of these initiatives, we urge the Department to reassess the pace they're going at as so many major shifts makes it very challenging for stakeholders to keep up. We appreciate the ongoing webinars and forums hosted by the Department in order to educate those most impacted. We can't emphasize enough the importance of ample communication and we urge them to maintain open dialogue with stakeholders to ensure these upcoming changes can be operationalized in an effective manner.

Looking ahead to the future, we are pleased to see the Department of Human Services is putting such a strong emphasis on employment for people with intellectual and developmental disabilities. As an Employment First State, The Arc of New Jersey believes that all individuals with I/DD should be considered for employment and that many can be and are successful when necessary supports are put in place to assist them. While we realize that employment won't be everyone's choice, employment is a critical component of a person's self-worth and the option to work should not be denied based solely on the existence of a developmental disability.

We are also excited by the new Supports Program which is a new Medicaid Waiver which will allow individuals with I/DD, living with family or in non-licensed settings, to access Division-funded services. We believe this waiver will offer individuals and families a variety of options that will keep them living successfully in the community. The Supports Program will provide all individuals with employment/day services and individual/family support services based on the person's assessed level of need. Enrollment will begin with a small group on July 1 and enrollment will continue to expand throughout the coming months. The Department of Human Services has reported that there will not be a waiting list for this program. While we are eager to see this Supports Program up and running, more work is needed to get this waiver to line up with the services offered through the Community Care Waiver (CCW). As currently written, some services will be accessible through the Supports Program that are not available to individuals enrolled on the CCW. In addition, there are some services that are available through both waivers, but because of inconsistences they could bill at different rates. This could be problematic for providers in the future, as they could serve two people in the same program with the same service and be paid differently for each one. We ask the Department to bring these waivers into alignment in order to avoid this potential problem.

Fee-for-Service

The shift to fee-for-service will fundamentally alter the way families and individuals access services and the way community providers deliver those services. While community providers are currently paid via contract reimbursement from the state in advance of service delivery, under the new system providers will now bill Medicaid directly after a service is delivered. If a served person is absent due to illness, hospitalization, vacation, family emergency, or any other reason, the provider will not receive payment. This will require providers to take on an entirely new business model in order to keep programs afloat.

In order to move to fee-for-service, the State initiated rate setting, a long process that included a national rate setter and then extensive evaluation of both the provider community and the range of services available in the State. Families and providers alike are apprehensive as we await the switch over. The Arc of New Jersey believes that certain aspects of fee-for-service will prove beneficial for those we represent. We believe the change should bring with it a level of fairness that doesn't currently exist. In theory, moving forward, all individuals with similar support needs will have similar funding for their programs and support services. In the current system, there are significant disparities in funding for programs based on when they first opened or what part of the state they're located in. Fee-for-service standardizes what rate is paid for a service and eliminates inconsistencies. The Arc of New Jersey supports this change and believes that moving forward a standardized rate based on the specific needs of an individual will prove beneficial. That is of course if rates are set appropriately and fully funded by the State. We are very concerned that at this time the Residential rate is only funded at 83% of the actual cost of service as was determined by the rate setter.

We are also concerned by certain aspects of the new system and how they will work once implemented. To ensure an individual with intellectual and developmental disabilities is receiving the proper supports and services, each person must first be assessed by the New Jersey Comprehensive Assessment Tool (NJ CAT). We understand that some kind of measuring device must be utilized, but the CAT should not be the sole apparatus for ascertaining a person's support needs. While the test may be well-crafted, standing alone it does not give the State the whole picture. Intellectual and developmental disabilities can often include complicated medical and behavioral components. The NJ CAT was not devised to take into account a constellation of components that include complex medical, mental health, and behavioral issues. Getting a full and accurate picture is critical in the fee-for-service world, as the results of the CAT determine a person's budget for services. If budgets are not appropriate and do not reflect an individual's needs, this will be highly detrimental to both the individual and the family. A lack of services will leave individuals without the services they require and families without the support they need to keep their son or daughter at home.

Another significant component of this shift is the elimination of case management and the move to support coordination. In the new system, individuals and families will work with a supports coordinator to arrange services with the budgeted money they are allotted to spend. The support coordinator will author the Individual Service Plan (ISP), provide the individual and family with the names of local community provider organizations and monitor the provision of services. An individual's success in the community will depend on the strength of their support coordinator as he or she will steer individuals and families through this process.

The Arc of New Jersey believes that some families will benefit from the fee-for-service system, because while in the past they were referred to a provider by the state, they will now have choice about where their loved one will receive services. This however will put additional burden onto the family members, as they will take on more of the responsibility surrounding their care.

Families are also likely to encounter challenges when it comes to spending their child's allotted budget. For example, if John Smith is budgeted to attend a day program three days a week, but John wakes up one of those mornings and is too sick to attend, the community provider cannot bill Medicaid because John didn't show up. In addition, John can't reallocate the money he would have spent for day program for another purpose. That is because those dollars were preauthorized by Medicaid for that specific day and for that specific service. That money is now lost and the individual loses out on the services that he needs.

In addition, we want to point out that on the housing side there is only a 5% percent vacancy rate built in for an individual living in a group home setting. This means a person living in a group home can only be absent for approximately 18 days per year. Whether an individual is out of the group home due to illness, hospitalization, family visits, vacation or any other circumstance, anything beyond the approximate 18 days will result in loss of payment to a provider organization. It should be noted that in the instance of residential services, it's not just a service but a person's home. We urge the Department to work with providers and families for an equitable resolution to address absences that go beyond the approximate 18 days; especially in the case of unexpected medical issues or hospitalizations that keep a person out of a group home for weeks or even months. In addition, there was no vacancy rate built into the day program rate and so that too will have a large impact on providers and the way they run that service.

We are also concerned that under the weight of the new requirements, some community provider organizations, particularly smaller operations, may not be successful in the new world. This could leave families without adequate options. Especially for those who live in the more rural areas of the state, this could prove particularly problematic. Another major challenge for community providers will be training requirements. While the new system requires a great deal of training for staff, this proposed new level of training was not built into the rates and it is not a billable service. Providers are mandated to train their staff but in the new world, funding for this critical requirement is no longer available. This will be a tremendous hardship for providers who are already adjusting to a number of other changes and new costs. Though we understand it's critical to have a well-trained work force, requiring so much additional training will be fiscally challenging to say the least.

Families are also confused about how their children will access housing in the new system. Housing is not a Medicaid reimbursable service. With this in mind, providers who currently operate group homes for people with intellectual and developmental disabilities will need to change how these homes operate. Served individuals will need to pay room and board, and as many do not work, the funds will come of out their Social Security Insurance (SSI) checks. We also know that the SSI will not be adequate to meet the room and board costs that are currently paid for by the contract and the Department has not addressed how the "housing gap" will be managed. For families who added their child to the Waiting List at a young age in order to ensure housing in the future, there is a lot of confusion about how the system will handle this critical issue.

In advance of the new system, providers are preparing their businesses and making adjustments in order to succeed in fee-for-service. However, the Department of Human Services is not delivering certain information to providers that will help them make important business decisions. This lack of information is preventing providers from moving forward with necessary preparations and this is problematic as the start date for fee-for-service nears. For example, how much care a person requires will dictate staffing levels at a group home. Without knowing where their served clients land on the acuity tiering, they cannot determine how many staff members to assign to a given group home or day program. The Department promised the provider community that this data would be forthcoming, but to date providers have not received it. Without these critical numbers, providers cannot make their businesses function in an effective manner.

Also in terms of business practices, we are advocating that the Department front community providers the needed funding for the first three months of service provision under the new fee-for-service system. This will give providers the opportunity to become more familiar with the new Medicaid billing system and to ease the transition from the current contract reimbursement system. This proposal will not cost the State any money, as any discrepancies will be settled at the end of the three month period. It is a good faith gesture that will get community providers up and running as they make this big change.

Home and Community Based Services Transition Plan

The Home and Community Based Services Transition Plan is a requirement in every state in order to come into compliance with a new federal rule put forward by the Centers for Medicare and Medicaid Services (CMS). The Arc of New Jersey supports the spirit of that federal rule, which aims to increase community inclusion for individuals with intellectual and developmental disabilities. However, the original version of New Jersey's Transition Plan included a number of arbitrary benchmarks, not required by CMS, which amounted to a one-size-fits-all approach that disregarded the many complexities and differences associated with intellectual and developmental disabilities. After a significant amount of pushback from families and advocacy organizations, more than 1,000 comments were submitted. In response to that feedback on the first draft, the Department revised the Plan. The Arc of New Jersey formally requested a secondary comment period due to the high level of interest from stakeholders, but that request was denied. The Department discussed with us the changes they intended to make to the final document, but the State's actual submission to CMS was not shared with stakeholders despite numerous requests to see and review it. We believe additional transparency on this issue would have resulted in a more open and less contentious process for all involved.

The revised Transition Plan now calls for a majority of a person's day in the community. According to the Department, this requirement can be met by either bringing an individual out into a community activity, or bringing someone from the community into the day program. Many of the State's community providers already offer these types of activities for served individuals.

Although we will have to see how the mandates are enforced, we believe the changes will provide more flexibility and will do a better job recognizing each individual's unique circumstances and desires while also balancing the realistic capabilities of community providers and their staff.

Every State has until March 17, 2019 to implement the requirements for home and community based services in accordance with CMS-approved plans and so there is a lot of work ahead of us in these next four years. As part of the implementation process, community provider organizations will be assessed by the Division of Developmental Disabilities and the State will determine whether a provider and/or setting meets the necessary criteria or whether remediation is required to come into compliance. We anticipate additional rulemaking and policy changes will also be part of the process. It is therefore important that with every step stakeholders are given ample opportunity to weigh in. The way New Jersey implements the HCBS Transition Plan will have ripple effects for years to come on people with I/DD, their families and providers. It is critical that we monitor this process closely to ensure the best possible outcomes.

Thank you again to the Chairman and members of the Committee for your ongoing commitment to people with intellectual and developmental disabilities and for the opportunity to speak with you here today.

New Jersey Senate
Legislative Oversight Committee
June 10, 2015

Mr. Chairman, Members of the Committee, my name is Robert Stack. My office is 16 Farber Road, Princeton. I have been supporting persons with disabilities in some capacity for the last 47 years. I am the President and CEO of Community Options. Our nonprofit was founded from my row home in Bordentown in 1989. Today, with almost 4,000 staff we support thousands of people with disabilities. Our mission is to develop housing and employment for persons with disabilities. We operate in multiple states.

Thank you for inviting me to testify on the ramifications of New Jersey going to a fee for service model. Community Options operates within a fee for service structure in most states with the exception of New Jersey. We know that there have been multiple starts and stops with this program.

As lawmakers and advocates for your constituents I want to commend you for how hard you work and offer gratitude that you take this subject matter seriously enough to convene these hearings. I would like to suggest that you consider options moving into a fee for service model.

In this model who is bearing the risk? Is it the state of New Jersey or is it the providers? What impact will this have on families? What impact will it have on the vulnerable people we support? Why are we going to this model? What are the goals of the change? Is it to serve the individual better? Is it to serve more people? Is it to reduce the waiting list? Is it to increase quality? If so, what is the research?

Individual lives are not as predicable as equations in a fee for service model. We need significant flexibility to accommodate the fact that some people with disabilities can and will cycle into crisis.

Payment systems cannot be narrowly defined because the community service system is highly evolved. Payment systems must accommodate a growing number of services and population characteristics. No one has a simple diagnosis. We all read about the higher incidents of autism in New Jersey. We all know about out of state placements. On a significant side note, today over a half a billion dollars is spent on 1,700 people in the New Jersey developmental center institutions.

If we go to a fee for service model, the question is what is going to be purchased? In the old days it was a straight up answer but now community integration is far more complex. In the late eighties when I was involved with the institutions there was a bundle of 24-hour service equaling one per diem. Now, the lives of people with disabilities are far different than the minimal constitutional standards of a bed and three meals. How did we get to the place we are at right now?

I learned that New Jersey DDD started exploring the idea of moving from expenditure based contract to a Fee for service (FFS) arrangement several years ago.

It started with strong consultant group. The principle met with families, consumers and agencies to determine how the rates should be structured. He indicated he worked in several other states determining an effective rate structure. It seemed to be a very good evaluation, interview and collection of data. They published the final report in July 2014. During this time a series of meetings were held and we were walked through the process of data collection and the determination of these definable rates. We understood the logic and felt comfortable with the outcome.

I am not really sure what happened, but that report was dramatically changed. Now we feel the program is not close to being defined.

In my opinion, transparency and consensus with all the stakeholders is needed to develop a model that will benefit those we support together. If correct systems are in place theoretically it should work without a problem. Maybe the Division of Developmental Disabilities should consider a working group to look at what will be effective and what does not work. I know that my colleagues and I are not afraid to roll up our sleeves and work together in unison with DDD.

I believe the Divisional staff worked hard on this but it needs more work. Our exposure so far has been meetings with limited representatives for questions and answers sessions. A great deal of time was spent discussing the process of tracking authorizations or consumer statistical analysis. These sessions were very unclear and many agencies asked important questions that are still left unanswered.

We can learn from other states. In Pennsylvania the move to this model became so bumpy that a lawsuit between the Commonwealth and the providers ensued. Some smaller nonprofits went out of business. All of us had significant cash flow issues until it was resolved.

There are collateral events that will impact the fee for service model. In Maryland, laws were passed to reflect provider rate payments to compensate for their decision to increase in minimum wage. Has this been addressed by New Jersey?

I have seen what was effective and what is not effective throughout the country. As lawmakers, I know that you do not want to spend time on being told problems. I would therefore like to recommend a potential solution. Possibly the Division and their contracted providers act in tandem as partners.

I suggest consideration be given for a one year time limited parallel pilot system. A system in which this model is operated as a dry run with simulated billings running payment numbers without actual payments. This will enable both the providers and the state to evaluate the efficacy of the program and adjust the system transparently and as mutually concerned stakeholders.

We plan this journey together as equals now with the welfare and safety of those who are most vulnerable to be given the highest consideration. We finish this journey after we all know that this process works and that most of the bugs are worked out of the system. We work in concert to achieve a way that all stakeholders work to ensure that the integrity of New Jerseyans with disabilities are preserved and they live the best possible life that we can offer.

Thank you.

SHA NJ
The Supportive Housing Association of New Jersey

June 10, 2015

Senator Robert Gordon and members of the NJ Senate Legislative Oversight Committee

Thank you for inviting me to speak on behalf of the Supportive Housing Association of NJ (SHA) about the NJ's Transition Plan and move to fee for service. The Supportive Housing Association of NJ (SHA) is a 17 year old membership organization comprised of over 100 members, predominantly housing developers and supportive housing providers all dedicated to creating affordable homes in communities throughout NJ with access to supportive services for people with disabilities and other special needs.

Medicaid Home and Community Based Services Transition Plan

The Transition plan aptly speaks to the central core values of supportive housing which honor an individual's right to live like others without disabilities, the opportunity for privacy, community integration, landlord tenant protections and the ability to select supportive services, based on individual needs.

While we commend the Department for keeping its focus on the individual rights of people to housing and supports in the Transition Plan, we have also cautioned the state to not be too prescriptive or rigid in its approach, and in the true spirit of choice, allow for a broader spectrum of housing options including those for people with disabilities who choose to live together in proximity to other people with disabilities.

CMS rules focus on qualitative experiences. While the rules clearly prohibit use of Medicaid HCBS in nursing facilities, IMDs, ICFs and hospitals, much is left open to choice, innovation and varied settings with the following community features – opportunities to seek employment, to engage in community life, to foster individual initiative, to live as others without disabilities, and to autonomy and independence.

Community integration must be held to a high standard, we agree, however the definition of integration should not exclusively be a quantitative measure. The decision to use a yardstick that requires no more than 25% of the tenants in a housing complex to live with disabilities (this is not found in the federal rules) focuses on percentages which is not always a gauge of quality of life or individual choice. Loneliness and separation from community can happen to a person living smack in the middle of Main St. but alone in a one bedroom apartment as it can befall individuals with disabilities living in close proximity whose only interactions are each other. Ultimately it is one's preferred experience and the availability of choices that are needed so that people can live how they wish and in a manner most comfortable to them.

SHA agrees with a standard and guidelines (otherwise we will go down that slippery slope and end up segregated and concentrated into disability enclaves), but we call for a flexible standard, that we believe would be accepted by CMS or at least successfully argued, such that DHS and providers can offer choices without sanction and within acceptable limits.

While I do not have numbers exclusively for people with I/DD, our estimates indicate that there are more than 41,000 very low income adults (adult households) in NJ living with disabilities who receive federal or state housing assistance in the form of public housing units or rental vouchers. Compare this with the approximately 120,000 adults on the SSI roles with disabilities who live on under $800 monthly. I would venture to guess that a large number of those without federal or state housing assistance (80,000) are living in substandard conditions, with aging parents, couch surfing or using high end cost centers such as emergency rooms, shelters, prisons and long term care facilities because they have no other place to live. We must seriously attend to the housing and support needs of these many thousands, which will require a great deal more flexibility in housing policy, models of housing and resources, both public and private.

Fee for Service

There is a sea change taking place in NJ within the DHS relative to the delivery of services for several different populations including those with I/DD. As we move from a contract based system to fee for service (and ultimately to a risk or managed care model), priorities and areas of caution are as follows:

1. As the system moves into Medicaid Fee for Service it is extremely important that the state provide a cushion for providers, many of whom do not have deep reserves, so that they can gradually transition to full Medicaid billing without the fear of a weakened infrastructure and potential agency closures. The provider system in NJ needs to be bolstered so that it can serve more people with I/DD and other special needs. As we see agencies affiliating and merging in this new system, we need to ensure that we keep the provider system strong and healthy.
2. In order to implement fee for service successfully agencies must purchase software systems that provide customized electronic client record keeping and Medicaid billing. Without these systems and without proper use of these systems (having reliable information about Medicaid requirements), NJ will be subject to federal audits claiming significant penalties for out of compliance billing and record keeping. We must provide the resources for these systems and effectively train our workforce to ensure that we operate properly in a Medicaid billing environment.
3. The newly created Supportive Housing Connection (SHC) is contracted by DHS/OH and resides in the NJ Housing & Mortgage Finance Agency (HMFA). The SHC's responsibility is to find new landlords, mediate landlord/tenant disputes, pay rental vouchers and conduct inspections of supportive housing and licensed units. While we do not object to this separation of housing from services, we want to make sure in the months ahead that the SHC enhances the system and that providers will not be prohibited from continuing to work constructively with tenants and landlords. Much of the successful work keeping landlord tenant relationships viable and secure is done at the grassroots level by agency staff.
4. A majority of the housing and services being developed in NJ for people with I/DD are for those at the highest end of the disability continuum – individuals with the most challenges – persons eligible for the CCW who are leaving the developmental centers (Olmstead), who are in emergency situations and who are returning home to NJ. This is important and necessary work and more are in need. There are also many thousands who are not and will never be on the CCW but live with I/DD at home with aging parents, in substandard rooming and boarding homes, on the streets or in high cost centers. These individuals deserve our assistance and support mingled with other public entitlements and the natural support system. We are more than eager for the new Supports Program to begin so that people can purchase services to remain stable in their housing choices, and we desperately need more state rental vouchers in the system if we are to begin the task of offering viable rental options (Opening 1,000 Doors budget campaign). Additionally the support coordination function must include expertise in housing coordination and supportive housing planning, otherwise families will remain frozen, unable to plan forward without quality assistance and guidance. The cost of care for these individuals will be substantially less than those who need 24/7 daily supports, and many will be able to secure even part time jobs to help them afford an affordable rental. But right now they are mostly unattended by us and need our help.

Thank you.

Gail Levinson, Executive Director

NJACP New Jersey Association of Community Providers
Advancing Quality Services for People with Intellectual and Developmental Disabilities

Testimony

Valerie Sellers, CEO

New Jersey Association of Community Providers

June 10, 2015

Good Morning. My name is Valerie Sellers. I am the CEO of the New Jersey Association of Community Providers, an association representing sixty two agencies providing services and supports to individuals with intellectual and developmental disabilities herein after referred to as I/DD. Thank you for inviting me to speak before you today.

Let me first start by saying that NJACP has been afforded an opportunity to work with DDD leadership throughout the rate setting process. They have solicited feedback and our input. I share this with you as this is not always the case with state regulatory agencies and for that we are truly appreciative. I'm hopeful that we will continue to have this cooperative working relationship. Having said that, you have asked that we address New Jersey's Division of Developmental Disabilities' transition from a contract-based reimbursement system to Fee-for-Service as well as New Jersey's State Transition Plan and I am happy to speak to both of these issues. I would preface what I say by simply stating that my intention or that of my association is not to disparage DDD but rather to share with you what concerns the providers I represent have in regard to the significant changes they are facing.

When I entered the world of I/DD, I was not surprised that the State would want to shift to FFS; in fact, I was surprised that it had taken this long given that most states throughout the country have already made this transition. I have now been with NJACP for two years and I have a much better understanding of the trepidation providers have with this change.

NJACP represents agencies that are very small to those that have a national presence. However, regardless of size, every one of my members continues to express concern regarding the many unanswered questions related to this new world of FFS. Over the last two years, providers have been told they must prepare for change. I also have encouraged them to do whatever is necessary to be prepared; however, I have found that making appropriate operational and financial changes are extremely difficult in the face of incomplete information, for example:

- Providers need access to complete and accurate information that will allow them to conduct the economic modeling necessary to determine what must be changed from a programmatic or financial standpoint or even determine if they will survive under FFS. We've encouraged providers that are financially vulnerable to speak with other agencies to discuss opportunities for collaboration or merger, however, they are hesitant to do so absent knowing what their position will be in this new world. While some information is forthcoming, there are many areas where absent having complete information, providers cannot move forward with their modeling or planning.

- Providers are being held to licensing standards that will simply no longer be applicable under FFS. Discussions are now taking place regarding these regulations but the reality is that amended regulations will not be in place prior to the move to FFS placing providers in a vulnerable position in relation to regulatory non-compliance and increased liability for failure to meet such requirements. Of note is that providers are now subject to *both* state and federal oversight. Relying upon "policies" does not provide any protection or assurance that an agency will avoid being deemed non-compliant or worse, penalized by CMS for not meeting their obligations as Medicaid providers. We need these amended regulations in place prior to the implementation of FFS.

- We now have hundreds of case managers that will be charged with overseeing quality. In response to concerns that we have raised, we have been assured that these individuals will go through training in preparation for their new role. This is absolutely critical as to date, they are duplicating the very work for which licensing is responsible, creating even more regulatory and administrative burdens for providers. I would add that moving forward any quality oversight provided through DDD must be based on objective outcomes.

These are examples of areas of concern that my members and I have and yet we are beginning the transition to FFS beginning this July, albeit with a gradual implementation. Worth noting is that providers of services to individuals with intellectual and development disabilities are not dealing only with a transition to FFS; they face a new process for providing housing, including the securing of leases, they must examine all of their programs and services to adhere to the State's Transition Plan and they must become familiar with a new billing system where mistakes could result in a loss of payment and financial penalties imposed by CMS. Any one of these changes could be overwhelming but collectively, they can easily lead to a downsizing of our field and, ultimately, limiting diversity of choice.

Let me conclude by saying I do not doubt in any way that DDD is committed to ensuring this transition occurs without compromising the quality of care provided to those with I/DD. As such, we are simply asking that enough time as necessary is taken to ensure each operation, policy and procedure associated with the transition to FFS be fully vetted and complete information made available to providers, consumers and families before moving forward with full implementation of this new system. We simply want to ensure that adhering to established deadlines cannot be at the expense of getting this transition "right" the first time.

State Transition Plan

Let me briefly speak to the State Transition Plan. I would like to thank DDD for making changes to the original draft of the Plan; these changes provide for more flexibility and, as a result, allow many more providers to continue offering services to their consumers. What continues to be at issue, however, is choice. We tell individuals that they have choice but in reality their choices are within those already determined by CMS or as defined in the state's plan. One would hope that CMS is also concerned about allowing more individuals to seek community inclusion but instead, the parameters they have established will make it far more difficult to find housing that will lead to that inclusion.

Providers throughout the state are eager to serve more individuals and see the waiting list for services eventually is eliminated. Too many restrictions will truly limit not only the choices individuals may make regarding where they choose to but also those that desperately want to live within the community but are not able to do so simply because the availability of allowable housing options.

And finally, I would love to provide any and all opportunities for individuals to be active members of their communities but first and foremost; they must ensure the safety and well-being of those they serve. They should not be placed in a position of deciding between complying with a mandate reflected in the Plan and ensuring those for which they have responsibility are safe. We look forward to hearing CMS' response to the revised plan.

Thank you again, Senator, and members of the Committee for inviting me to be here today and for your continued support of consumers, parents, family members and providers.

Comments from Nina Stein White, mother of 3 autistic spectrum individuals, farmer, baker
201-787-7366
Nina@cowsoutside.com

I am here to express concerns that are shared by the families and guardians of severely autistic individuals who exhibit extreme behaviors that require exceptional interventions and behavioral supports. Our youngest son Jacob is among the thousands of New Jersey citizens who are self-injurious, aggressive, and destructive. He needs and deserves the sanctuary of highly specialized and controlled settings. Centralized campuses, intentional communities and farmsteads have proven to be the safest and most economical models for supporting these individuals in creating a safe and productive life. New Jersey's revised statewide transition plan continues to contain a ban on "co-located" settings which are programs where the residential and vocational program are located on the same property. Our son lives on such a setting and like so many others requires this option in order to keep him safe.

My husband and I also have two adult children with Asperger's Syndrome. They are both highly intelligent, and have completed college level course work. Our eldest drives, and will be performing in the NY Renaissance Festival this year. Our middle son has had some struggles, but he has chosen a career path and is working towards it.

There are people that advocate for the universal inclusion of all people with disabilities. I know, first hand, that it's not universally appropriate. In fact, when DDD placed our son Jacob in a group home, they could not manage his behaviors,he injured himself, the ambulance called the police,and the police pepper-sprayed him!

Jacob has minimal speech capabilities. He cannot say "something hurts" or "I'm frightened". On a regular basis, he has explosive and dangerous self-injurious episodes that will erupt suddenly, for no apparent reason.

He requires 5 trained staff to prevent him from striking his own head violently. Even though he says, "calming down" while he is hitting himself and biting his own hand, it can take between 5 and 30 minutes before he can regain control with their assistance.

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Recently, during our regular outing to a chinese restaurant, Jacob went from happy to full-on tantrum without warning. We were not able to calm him, and he ended up running around a parking lot for 15 minutes, striking his head repeatedly. When we tried to intervene, he tried to bite us. The police officer who came was not equipped to help us to restrain him. After about 15 minutes, Jacob's storm had climaxed, and we were able to get him into the car and bring him back to campus. Fortunately, on this round, he did ,not do any permanent damage to himself or others.

Now, Bancroft is able to provide appropriate behavioral and psychiatric interventions for jacob by using a centralized campus model. He is now able to remain in good control most of the time, with the help of Bancroft's direct care staff and on-site supervisors. With a fluid interplay between his residential and vocational program, Jacob is in good control because he is as engaged as possible throughout his days.

There is no way to create this intense behavioral support in a group home nor in an apartment in an integrated setting. There are not psychiatrists and behaviorists sufficient to provide support for the individuals who require this level of support in a 4 bed group home.

The need to transport Jacob to another location for intervention is not feasible due to the suddenness, intensity and frequency of his behaviors. If Jacob were forced to go to a day program in a separate location from his residence, he would likely be more isolated. If he couldn't be transported,he might miss his whole day of programming. And if he wasn't engaged by work, he would be less controllable, as he needs engagement to stay focused and thus calm. On many days if forced to travel to another location for his vocational program, he, staff, and even members of the public who might be sharing the road would be recklessly place in danger.

Sadly, low functioning autistic individuals like our son haven't the awareness to wish to be part of the community at large. In fact, the unpredictable nature of "the outside world" can be terrifying to those who have impaired processing and a need for sameness.

Getting Jacob into a more mainstreamed life can be part of a long-term goal, but ignoring other current needs to serve that end will be (in Jacob's case) reckless and dangerous.

Most autistic people have severe anxiety, which is often triggered by transitions and even minute changes in routines. Campus programs, intentional communities, and farm communities provide consistent routine and reduce anxiety. This improves behavior and productivity.

This state needs to keep its campus programs for those who benefit from them. For our son Jacob's population, we cannot look at housing as a separate issue from day programming. Jacob and his peers do not need housing provided by the state for financial reasons. They need comprehensive programming designed by people with expertise in this difficult area. With today' s open door policies and excellent laws in place to protect the rights of these vulnerable individuals, co-located programs can provide excellent care and should be supported as a necessary option for families.

And I would add that we could do great things for all of our communities if we removed the outdated stigma of the word asylum. What is wrong with people living on a farm and growing food and inviting the public in to buy? I do it every day, and my life is exceedingly fulfilling! My farm is certainly not an institution and neither is Jacob's current program.

June 10, 2015

Presentation to Senator Gordon and Committee

Thank you Senator Gordon and Committee members for your interest and this opportunity to speak with you about the State's Transition Plan developed by the Division of Developmental Disabilities (DDD) and its impacts on programs like ours. My name is Nadine Kaiser and I am the Executive Director of the Opportunity Center in Fair Lawn NJ.

We know you want to focus on the State's Transition Plan and we will restrict our comments accordingly. However, we thought a more in-depth treatment of the issues as well as some information about our program might help give context and clarity to our comments. Toward this goal we have provided copies of our calendar that helps to illustrate the range of activities that we offer as well as copies of a presentation expanded to provide details that we have excluded from our oral presentation in the interest of staying within the allotted time.

The Opportunity Center has provided a day program for roughly 25 adults with intellectual and developmental disabilities (primarily Down Syndrome and autism) for 50 years. We are an independent, not-for-profit organization. We are, however, a part of an association of small day programs like ours. We are sure that other members of that association would also be happy to share their thoughts.

We are not a "contracted agency" which simply means that we have never been subject to state oversight. That makes our challenges and culture shock a bit greater than some other programs that currently have contracts with DDD.

Our Greatest Concerns

Following are some of our greatest concerns about the changes that are required by DDD and which are found in the Transition Plan, the Policy Manual, and the Fee for Service Rate Schedule or which have been communicated during Webinars. Each of these concerns is greatly exacerbated by the speed DDD is moving and the timing of required changes: These primary concerns are:

- The New Rates and what they mean to our ability to balance our budget
- The requirement to provide transportation
- Complying with NJ's "Work First" priorities
- The requirement that there not be a single facility schedule for all participants – each individual should have a unique schedule that they choose and which reflects their interests and goals.
- The Community Inclusion requirement

Opportunity Center Fair Lawn NJ

DDD further indicated in the revised Transition Plan that the requirement to participate in activities within the community could be met by either traveling into the community to integrated program activities or alternatively to integrate activities at the day habilitation center by including nondisabled members of the community.

While the concept of bringing nondisabled into the Center is intriguing, it raises some concerns.

First, will we be able to attract a sufficient number of nondisabled individuals into our Center? How many is enough? If we invite the community and they don't come, do we fail to meet the requirement?

And, even more importantly, how will we make sure that those individuals who join us from the community are not a threat to our disabled participants? Right now, we carefully vet volunteers and others who come into the center. Would we have to do that with those who want to join us in activities? Would anyone join us with those stipulations and could we be comfortable without them?

Regarding the alternative of traveling into the community, we have several concerns. First, it raises the staffing and financial concerns noted earlier with choice and further raises the question of who has to find all these programs and make sure that they are appropriate for and will accept our individuals? We certainly aren't being compensated for those efforts and will have to pull staff from client service to do so.

Finally, the question that should really be asked first – is it right for our clients to travel into the community or have the community come into the Center. We have a number of clients who do not deal well with change. Adopting a new schedule, being in a new setting, meeting new people may all lead to high levels of stress and inappropriate behavior. Other clients are sensitive to stimulation; noise, lighting or other stimuli which we can control to a large degree in the Center could be problematic in the community. Sure, there are certain to be other programs and other individuals for whom this change will be advantageous and appropriate. But do we have to force it on the more severely disabled for whom it may be traumatic?

Our suggestion is to simply slow down. Maybe do a little experimentation with a few programs to see what is viable and what is not before you completely dismantle the programs that operate successfully today and in many cases have done so for decades.

Training Requirements for Staff

Finally, I just want to note that we started adding up the hours involved in the training requirements for staff and found that they are significant –about 25 hours in the first 30 days and over 70 hours in the first year, the equivalent of about 2 weeks of work. While we are in favor of most training, the time frames that they must be completed within are perhaps a little too short. Moreover, we can't really afford to have staff train while at work and we pay them too modestly to expect them to train without compensation – so training will put a financial burden on the day program budgets. Until we know how our budgets will fair in the new fee for service world, we can't know whether that financial burden will be too great for day habilitation programs like ours to absorb.

In summary, in the best interests of individuals served by DDD, we hope that DDD will slow down, delay implementing changes, experiment and recognize that there is a broad range of individuals with disabilities. For some of these individuals, choice and flexibility and community inclusion will improve the quality of their lives. For others, in the way DDD is introducing that choice, flexibility and community inclusion, it will diminish the quality of their lives.

Thanks for your patience and attention to these important issues. I would be happy to answer any questions that you have.

Opportunity Center
Fair Lawn NJ

Additional Written Comments Not Included in Oral Presentation to Committee

In the interest of time, the oral comments given to the Committee represent the highlights of our concerns, which we have fleshed out a bit in the written comments which we have provided below. In addition, if you would like to see an independent review of the issues, there is an excellent article in the Atlantic that can be found at http://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455. The article does an excellent job of explaining why flexibility in the approach taken by DDD is essential to a successful outcome.

Perhaps the best way to illustrate the degree of change that DDD is requiring of individuals and day programs alike is to start out by telling you a little about what our program is like currently. If you would like to see for yourselves, you are more than welcome to visit the Center. We are sure you will come away with an understanding of why we feel changes in DDD's rules would be prudent and appropriate.

Highlights of the Opportunity Center Program

We do not provide transportation to our program at the beginning of the day or transportation back home at the end of the day. Clients come from all different directions and are transported to us by either Access Link, vans operated by group homes or family members.

We receive $75 a day from each client. We generally fund raise to make sure that families do not have to pay for anything else in our program (i.e., shows, movies, trips, etc.). Our annual expenditures are pretty close to being in balance with our annual income.

We travel as a group (i.e., all 25 clients and staff) into the community each week for activities at the library, gym, town pool, parks and somewhat less often than weekly to special activities such as plays, movies, museums, fairs, etc.

Most of our activities take place at our center. We bring in instructors in speech, music, art, dance, pottery, zumba, yoga, tai chi, etc. to supplement the leadership of our staff and to offer clients a diverse program, stimulating body and mind. We have computers available for use by clients and a garden in which our clients grow most everything you can imagine, including award winning flowers and delicious vegetables that we harvest.

We also contract with a company to do light repackaging of combs and other items. This is intended to give clients the experience and satisfaction of working. While the skills that they acquire would be helpful if they moved on to competitive employment, very few of our clients have ever engaged in competitive employment. The money earned, which is modest, is used to pay for a special lunch once each month.

Our clients and their families are happy in our program. Feel free to ask any of them.

Proposed Changes

Why is DDD Proposing Changes?

While we are happy to share our understanding of why changes are being required, perhaps you already know or would prefer to hear that from DDD. If you want our understanding of the motivation for change, it is the following:

In order to receive federal money through Medicaid, NJ must submit a transition plan which moves the state towards greater conformance to principles established by the Centers for Medicare and Medicaid Services (CMS). Together with principles regarding work that New Jersey advocates, we can summarize the principles as requiring:

- Greater community integration among those served by DDD and less institutionalization. More opportunities to interact with those not served by DDD.
- Greater choice in the lives of those served by DDD and the opportunity to have experiences similar to those available to individuals not served by DDD.
- Everyone to work towards competitive employment (in a non-sheltered environment for a pay of at least the minimum wage).

Some Details of the State's Transition Plan:

While much of what we will address comes from the state transition plan, some comes from other resources – including things that have been said during meetings and Webinars, the Manual that DDD released recently and the rates that they published in May.

Following are some excerpts from the NJ State Transition Plan. They will give you a sense why some who are advocating for high performing disabled individuals want the plan to move forward without change.

For example, the transition plan mandates that our program must ***provide opportunities for individuals to:***

- Seek employment and work in a competitive integrated environment
- Engage in community life
- Control personal resources
- Have the same access to the community as people who are not disabled

Further, our Center must ***promote***:

- Individual initiative

- Autonomy, and
- Independence in making life choices

Finally, the Statewide Transition Plan ***Day Program Specific Requirements Include:***

- DDD will focus on Centers providing competitive employment activities for all
- Day services must be provided in a community based setting, and
- Activities must be chosen by the individual

While these could all be reasonable and even desirable objectives if adjusted to the individual, it is the lack of flexibility that both the words written and said by DDD that give us pause. Following are some other excerpts from the Transition Plan that add clarity to DDD's interpretation of the words they have written.

"The facility should serve as a hub in a model that maximizes community integration and ensures opportunities to interact with the broader community of non-HCBS recipients and participate in activities that are not solely specifically designed for people with disabilities but are designed for the broader community of non-HCBS recipients."

"Individuals should spend the majority of their time in activities they choose that reflect their individual interests and goals."

"There will be no overall facility schedule for participants – each individual should have a unique schedule reflecting their interests and goals."

The Fair Lawn Opportunity Center has been operating throughout its 50 years serving a population for which most of these lofty and well-meaning goals are largely unrealistic.

What's The Problem?

Among the greatest challenges that DDD is creating is the need to move very fast. It would be helpful if they backed off the attempt to introduce changes July 1, 2015. They have simply not yet given us sufficient time or detail on how changes are supposed to work.

Challenges to Client Well –Being That DDD Requirements Represent.

Let's briefly discuss how the requirements noted above have been clarified by DDD in meetings, albeit ones that preceded the latest draft of the Transition Plan and how they have the potential to undermine the welfare of individuals who have greater challenges from their disabilities.

Competitive employment opportunities mean working outside the Center in a job paying at least minimum wage. While there is an understanding that this is "the goal" and it may take some time for some to reach it, we see no evidence that DDD understands that this goal is not attainable for some disabled individuals. To make them work towards the unattainable seems like

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a waste of time, resources and energy. Wouldn't it be better to at least give them the dignity of working in a noncompetitive way, as we do in the Center currently? All that said, we understand that there is a tendency to have a knee-jerk reaction to change that we must resist. We have to be careful not to stand in the way of individuals who can overcome the challenges and achieve a level of growth beyond expectations. Perhaps the state and other interested parties can work on some way of minimizing the likelihood that any individual be held back. However, for those for whom it is agreed work in a competitive environment is out of reach; let's do the best we can to make their lives full and rewarding, as we feel our current work program does. All you have to see is the pride that many take in their work efforts to understand that it fulfills a need.

Day services must be provided in a community based setting. While one would think that our facility on Fair Lawn Avenue would meet the definition of "community based", what DDD has said in meetings and indicated in writing is that they want the majority of activities in which clients participate to include individuals who are not disabled. DDD has said that this requirement can be met in the Center, by inviting members of the community to join in our activities or alternatively by traveling to integrated activities in the community. Further, to the extent that we travel into the community to meet the requirement, DDD has stated that we should do so ***in small groups, preferably 4 individuals but not to exceed 6 in order to maximize "interaction with the non-disabled community".*** While there are enumerable challenges to meeting this requirement, the main objection is that it does not take into account the ability to adapt of the individual and their energy level. Many of our clients and particularly those with an autism diagnosis do not adapt well to new environments or people they don't know. When we travel into the community as a group of 24 (plus staff), individuals have the presence of familiar faces to comfort them. Some will have extreme stress from the proposed community integration. The stress of the situation will cause some individuals to exhibit inappropriate behavior. How welcome will we be in the community activities after such incidents?

Many individuals with developmental disabilities have other health issues that limit their stamina and/or are older with the associated reduction in endurance. Being in the Center allows them time to rest and recover from activities.

If we have to travel more than half the time to take clients to activities in the community, they will tire just getting on and off the van, not to mention how much of their day will be spent getting on the van, riding to programs and getting off the van. Many of our clients cannot seat belt themselves and need help with getting on and off the van – so it will take some time and energy that can be used more valuably.

As noted in our oral comments, the concerns with bringing the community into the Center involve the safety of our clients and, if those concerns can be satisfied, the ability to actually attract sufficient numbers of non-disabled individuals into the Center. How many is enough?

Challenges That DDD Proposals Represent For Day Program Providers

While the welfare of our clients is our primary concern, we can't stay in business if we can't balance our books. And, we can't implement requirements that need further clarification.

Balancing the books – today -- At the present time, we receive $75 a day for each client covered by Medicaid. That amount is adequate and while there are a few bumps, our budget has largely been in balance with the help of a small endowment, volunteers including an active Board and fund raising. For the $75 fee, clients can stay as few hours as they want or from opening to closing (which is around 7 hours or a little more). At this level of funding we can afford to maintain 6 staff members for the bulk of the day and with our 24 clients, run a ratio of roughly 1 staff member for every 4 clients. Together with our many volunteers, we find this staffing to be adequate. We do not provide transportation to the program in the morning and from the program in the afternoon but do transport our clients from the Center to the many community, cultural and recreational activities in which we participate.

Balancing the books – after changes are implemented – There are three aspects of the changes that present financial barriers to our ability to provide high quality service to our community. They are:

- The level of reimbursement
- Choice, and
- Staffing for small group community visits

The level of reimbursement – We really can't figure out our financial situation until we understand how the "choice" and "small group community visits" will work in practice. However, even setting aside those two issues, we are still unable to tell you what our financial situation is because DDD has not given us the information we need to assess the level of reimbursement that we will receive in the future. Yet they continue to say that the new financing structure will be used as of July 1 for new clients and over the next 18 months for all other clients. The new financing structure requires that we report activities in hourly or smaller time modules in a format that they have yet to communicate. We have been told that we will be reimbursed at an hourly rate that differs based on the level of need of our clients (which will be translated into an assigned tier for each client).

Since DDD has announced that they will reassess all eligible individuals over the next few months as a first step in assigning tiers, we won't know into which tier our clients will fall for some number of months. So even if we receive a new rate schedule, it will not give us the information needed to estimate our income.

In terms of a rate schedule, DDD has issued three separate rate schedules to date. That last rate schedule also included, for the first time, a requirement that Day programs provide transportation from the client's residence to the Center in the morning and back to the client's residence at

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night. While some programs provide transportation currently, many (including ours) do not. Clients make their way to Day Programs via Access Link or another bus service or with family members or with their group-home vehicle. Because the requirement is new, we are not sure what it will mean in practice. Will parents and group homes jump on the opportunity to transfer responsibility to us? Exactly when do we have to assume the responsibility for transportation? Will the reimbursement level the state provides cover the cost of purchasing and maintaining vehicles for transportation? That is an awful lot of uncertainty for a change that appears to be imminent.

Choice and Staffing – While we offer some choices in our current program – for much of the day, all 24 of our clients participate in the same activities at the same time. This is particularly true of visits to sites outside our Center but also applies to classes that third parties come to the Center to offer. Are individuals given sufficient choice if they can choose to work on an art project, computers or read a book rather than attend a class in zumba at the Center. If a client wants to attend yoga class at 2PM and we don't offer it at the Center at that time do we have to find a special activity at the selected time in the community for such a client? Is it our responsibility to take them to that activity in a situation which may require one to one staffing? How will we be reimbursed for that cost? While we don't think that degree of choice is mandatory, we really don't know what degree of choice is acceptable.

In terms of small group visits into the community, we estimate that such an approach will increase our costs dramatically. Consider that each time we send a group of 6 individuals into the community they need to have two staff members with them If we send our 24 clients in 4 groups of 6, each with 2 staff members, we need to have 8 staff members and 4 vans to accomplish that. That is 2 more staff members and one more vehicle than we use currently. That would imply a roughly 33% increase in our costs. Suffice it to say that we are concerned that we won't be financially viable in the future if we have to travel into the community in groups of 6.

In terms of competitive employment, the few situations in which we have tried to help clients with job placements lead us to believe that there are very limited opportunities for clients to work in setting that are appropriate for their issues and abilities. Has DDD done any analysis of the real number of available opportunities? Have they determined who will find those opportunities and how they will be compensated?

Similarly, has DDD inventoried the extent of appropriate community activities offered that will integrate both disabled and non-disabled in a single class/venue? Whose responsibilities is it to find these program offerings? The Support Coordinators? The Day Programs.

Our Wish List

Slow Down – While we would love a waiver or partial waiver from the requirements on the grounds that we are a small program serving a special population, we recognize that waivers may not be in the offing. So, focusing on what we feel is both necessary and realistic, we think the

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state is moving too fast – leaving inadequate time for feedback and for the experimentation that will be needed to understand, in detail, how things can work well and what will need modification. A staged introduction of changes is far preferable and will lead to fewer bad outcomes and disruptions for clients. And please drop any reference to a July 1, 2015 start-up. There is no reason to pick a date that nobody is ready for. Let's get ready first.

Explain and Partner – If and when the state is confident it has a model that can work, explain it in practical, detailed terms. To date, we haven't heard such an explanation from anyone at the state level and we are concerned that even they do not know how this is actually going to work from a practical perspective. The state should not act like Moses, throwing down commandments from the top of the mountain. They should form a partnership with interested parties to make the required changes meaningful and successful. Help us to figure out how to execute their vision.

DDD has told us we will have to submit our billing information in a new way beginning July 1 yet we have not received any guidance on what will be required. Also, they tell us that due to Medicaid oversight, we will be subject to greater audit scrutiny but to date have provided no guidance on the data that we will need to maintain to satisfy Medicaid. As noted at the opening of this memo, since we are not a contracted agency currently, data retention and potential audits are new to us. DDD has recently scheduled two seminars which will be led by the fiscal manager and cover billing. However, we are limited to having only two people attend the seminars and we don't know whether they will address all of our concerns. Given that the billing change is only three weeks away for some individuals, wouldn't it be better to slow down and delay implementation?

We are willing to make our best effort to adapt to rational changes introduced with proper guidance and notice and which prioritize the welfare of all the disabled who receive Medicaid assistance. But that is not what has occurred to date.

Please note that we believe the thrust of the State's proposal is to make agencies more responsive to the needs of the individual client. That has always been the mission of the Opportunity Center. We have stayed small by design and have served a population that could easily get lost in larger settings. We are not only unique but effective as well. Comments by parents and guardians express this view constantly. It would be a shame on many levels if we have to shut our doors because the changes we are being asked to make are inappropriate in some cases, unclear in others and unaffordable in their entirety.

The Opportunity Center

Sample Calendar

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1)	**2)** **8:30** Light Packing **8:30** Books **8:30** Art **10:00** Bowling **12:00** Lunch **1:00** Jazz Concert **1:00** Gardening **2:30** Light Packing **2:30** Computers **2:30** Program Cleanup	**3)** **8:30** Light Packing **8:30** Books **11:00** Xylophone Name That Tune **11:00** Shopping **12:00** Lunch **1:00** Yoga **1:00** Computers **2:30** Light Packing **2:30** Art **2:30** Program Cleanup	**4)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Sports in the Park **11:00** Gym **11:00** Arcade **12:00** Lunch **1:15** Music & Dance w/ Greg **1:15** Reading **1:15** Gardening **2:30** Light Packing **2:30** Books **2:30** Computers	**5)** **8:30** Light Packing **8:30** Books **11:00** Library Program **11:00** Library Independent **12:00** Lunch **1:00** Tai Chi **1:00** Music & Dance **1:00** Light Packing **2:30** Art **2:30** Program Cleanup	**6)** **8:30** Light Packing **8:30** Books **8:30** Art **9:00** Speech **11:00** Accordion **11:00** Therapy Dogs **12:00** Lunch **1:00** Reading **1:00** Gardening **2:30** Light Packing **2:30** Computers **2:30** Program Cleanup	**7)**
8)	**9)** **8:30** Light Packing **8:30** Books **8:30** Art **9:00** Cooking **9:00** Gardening **10:00** Bowling **12:00** Lunch **1:00** Yoga **1:00** Books **1:00** Computers **2:30** Light Packing **2:30** Program Cleanup	**10)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Zumba **11:00** Bingo **12:00** Lunch **1:00** Music & Dance w/ Pete and Lenny **1:00** Shopping **2:30** Light Packing **2:30** Books **2:30** Program Cleanup	**11)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Gym **11:00** Sports in the Park **11:00** Arcade **12:00** Lunch **1:00** Computers **1:00** Gardening **1:00** Light n Lively **2:30** Light Packing **2:30** Program Cleanup	**12)** **8:30** Light Packing **8:30** Art **11:00** Ceramics **11:00** Let's Make a healthy salad **12:00** Lunch **1:00** Music & Dance w/ Bert **1:00** Books **2:30** Light Packing **2:30** Program Cleanup	**13)** **8:30** Light Packing **8:30** Books **8:30** Art **9:00** Speech **11:00** Arts and Crafts **11:00** Gardening **12:00** Lunch **1:15** Yoga **1:15** Computers **2:30** Light Packing **2:30** Program Cleanup	**14)**

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
15)	**16)** **8:30** Light Packing **8:30** Books **8:30** Art **10:00** Bowling **12:00** Lunch **1:00** Yoga **1:00** Gardening **2:30** Light Packing **2:30** Computers **2:30** Program Cleanup	**17)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Art of the Masters **12:00** Lunch **1:00** Music **1:00** Computers **2:30** Light Packing **2:30** Program Cleanup	**18)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Sports in the Park **11:00** Gym **11:00** Arcade **12:00** Lunch **1:00** Frank's Music **1:00** Reading **1:00** Gardening **2:30** Light Packing **2:30** Program Cleanup	**19)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Library Program **11:00** Library Independent **12:00** Lunch **1:00** Tai Chi **1:00** Music & Dance **2:30** Light Packing **2:30** Program Cleanup	**20)** **8:30** Light Packing **8:30** Books **8:30** Art **9:00** Speech **11:00** Mary's Crafts **11:00** Gardening **12:00** Lunch **1:00** Baking **1:00** Computers **1:00** Music **2:30** Light Packing **2:30** Program Cleanup	**21)**
22)	**23)** **8:30** Light Packing **8:30** Books **8:30** Art **9:00** Cooking **9:00** Gardening **10:00** Bowling **12:00** Lunch **1:15** Peter's Music **1:15** Computers **2:30** Light Packing **2:30** Program Cleanup	**24)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Baking **11:00** Bingo **12:00** Lunch **1:00** Music & Dance w/ Margie **1:00** Shopping **2:30** Light Packing **2:30** Program Cleanup	**25)** **8:30** Light Packing **8:30** Books **8:30** Art **10:00** Gardening **10:00** Cooking **11:00** Gym **11:00** Sports in the Park **11:00** Arcade **12:00** Lunch **1:00** Computers **1:00** Light n Lively **2:30** Light Packing **2:30** Program Cleanup	**26)** **8:30** Light Packing **8:30** Books **8:30** Art **11:00** Healthy Hour **11:00** Let's Make a healthy salad **12:00** Lunch **1:00** Harp to Heart **1:00** Shopping **2:30** Light Packing **2:30** Program Cleanup	**27)** **8:30** Light Packing **8:30** Books **8:30** Art **9:00** Speech **11:00** Arts and Crafts **11:00** Gardening **12:00** Lunch **1:15** Yoga **1:15** Computers **2:30** Light Packing **2:30** Program Cleanup	**28)**

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NJCDD
New Jersey Council on Developmental Disabilities

Stephanie A. Pratico *Chair*
Kevin T. Casey, *Executive Director*

Testimony for the New Jersey Legislative Oversight Committee
June 10, 2015

Chairperson Gordon, Vice-Chairperson Weinberg, members of the Committee, good morning and thank you for the opportunity to speak to you this morning. My name is Kevin Casey, and I am the Executive Director of the New Jersey Council on Developmental Disabilities. The Council is an organization created under Federal statute that is responsible for advocating for people with developmental disabilities and their families. Each state has a similar organization created under the Developmental Disabilities Assistance and Bill of Rights Act. The Division of Developmental Disabilities is currently involved in a wide-ranging effort to reform the service system for people with developmental disabilities. This includes:

- filing a transition plan to come into compliance with new federal rules,
- attempting to bring back to New Jersey individuals who have been supported out of state,
- changing from a grant funded program to a program that is funded by a fee for service model,
- changing the manner in which case management is done, and
- complete re-assessment of all (approximately 20,000) persons currently served by the program.

Some of these efforts have been required by the Federal Government and some have not. While we believe that these efforts are well intended on the Division's part, there are several serious concerns that need to be discussed and action taken for remediation.

1. Each of the efforts mentioned above is massive in nature, and by themselves require significant planning and time to implement. The simultaneous transition of the various has made it very difficult for families and consumers to understand, and to be a part of the planning process. In addition it has caused considerable and unnecessary angst among families and self-advocates.
2. In the matter of both the Transition planning, and the Return Home New Jersey effort, self-advocates and families have **not been given an opportunity to appeal** to an independent body if they feel that the plan set up for themselves or their family member is inadequate. *We recommend that the Division set up a separate independent appeal process self-advocates and families may use if they feel that the plan developed is not adequate. This is how we can insure that we deliver a person centered plan and not try have an individual fit into a state developed model.*
3. Most importantly, there is a widely held feeling from self-advocates, families, and providers, that **they have not been involved in the planning process for any of the activities, nor have they been adequately involved in the discussion of whether plans are adequate once completed**. We believe that it is crucial for the Division to set up a permanent advisory structure that all such plans must go through before they are completed. This structure should include self-advocates, families, providers, and other advocacy groups. It should be required to meet on a regular basis to hear Division plans, to comment on them, and to hear division response on their plans. This advisory structure should always have a majority of self-advocates and families in its membership.
4. If the Division is unwilling to set up such a structure voluntarily, then the Legislature should consider requiring it by statute.

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The New Jersey Council on Developmental Disabilities is ready to work with the Division, other advocacy organizations, trade associations and directly with self-advocates and families to facilitate these initiatives.
I am happy to address any questions that you might have. Again, thank you for the opportunity to testify today on these critical issues.

Kevin T. Casey
Executive Director
New Jersey Council on Developmental Disabilities
kevin.casey@njcdd.org

CAROLYN PURCELL REICHENBACH
267-980-9589
LOUGHMOE@YAHOO.COM

June 10, 2015

Senate Oversight Committee
State of New Jersey
Trenton, NJ 08625

RE: <u>Committee Review of Return Home New Jersey</u>

Dear Members of the Senate Oversight Committee:

I would like to thank Senator Gordon and each of you for the opportunity to speak today about the Return Home NJ initiative ("RHNJ").

My 49 year old brother Richard has been profoundly disabled since birth. His more significant diagnoses include autism, epilepsy, severe intellectual impairment and tuberous sclerosis (a rare condition in which benign - but largely inoperable - tumors develop on various organs, impeding their function). Nevertheless, Richard's friendly demeanor, easy-going personality and big heart have endeared him to many people throughout his lifetime.

For more than 30 years, Richard has happily resided at Woods Services in Langhorne, PA, where his progress has been both continuous and substantial. He works 5 days a week in the staff cafeteria on-campus; gathers with friends in town for dinner on Fridays; attends services at the local Episcopal church on Sundays; and enjoys regular visits with members of his immediate family. Richard is happy, safe and thriving at Woods.

RHNJ threatens to change all of this for Richard and hundreds of others similarly-situated to him, by compelling their relocation to unfamiliar group homes, in unfamiliar towns with unfamiliar staff and unfamiliar housemates....often farther away from their families. I am compelled - as are many others in this room today - to ask WHY? WHY? DDD claims to be pursuing these relocations under the guise of community integration, fiscal responsibility, and enhanced family nexus. In my opinion - as both a lawyer and Richard's guardian - these reasons ring hollow.

Richard - and other individuals at campus-based facilities like Woods - are already more integrated into the community in which they live than they ever could hope to be residing at 4-person group homes sprinkled across NJ. Richard knows well over 500 people on campus and over 150 people off-campus; and virtually every visit into town for the two of us culminates in someone greeting Richard and immediately inquiring - with an eye to Richard's security - as to who *I* am. There is no greater comfort to me than to know that Richard has an army of people - both on and off campus - concerned about his well-being and watching out for his safety.

DDD's fiscal responsibility argument is just as illusory. Richard's placement costs out-of-state are significantly below the average out-of-state placement cost of $115,000 and the average in-state placement cost of $202,000. Further, because Richard lives in a 4-person, detached home off-campus, his placement at Woods would be eligible for Medicaid reimbursement if DDD were to pursue it. For reasons unclear, DDD has intentionally decided not to, however.

Lastly, DDD's family proximity argument is equally weak. My husband, my children and I all live near Woods by design, so that we can have regular contact with Richard. Any relocation of Richard at this point would move him further away from the members of his immediate family who visit with him the most.

Even if there were a scintilla of truth to the reasons DDD cites, relocation remains inappropriate for Richard and many others similarly-situated to him. DDD - *not my family* - placed Richard at Woods over 30 years ago, asked him to adjust (which he ultimately did) and has agreed for the past 3 decades that his placement at Woods is appropriate. Therefore, DDD should be estopped from changing its plan this late in the game.

Notwithstanding the evident cracks in DDD's justification for RHNJ, the initiative itself is flawed. It imprudently applies a "one size fits all" policy to NJ's disabled out-of-state residents, entirely ignoring the vast needs of this most vulnerable segment of NJ's population. In addition, RHNJ fails to take into account whether relocation is actually in a disabled person's best interests... a shocking omission, given that NJ law mandates a "best interest" standard for all relocations.

Over the course of this past year, I have immersed myself in NJ's disability laws, educated myself about Medicaid reimbursement, spoken with dozens of families affected by RHNJ, and met with many legislators. As a result, I have a fairly sound grasp of RHNJ and recognize that many of the statements being made about RHNJ are misleading or simply false. Accordingly, I would like to take a brief moment to correct some of these more significant misstatements by giving you these facts:

- The average in-state placement ($115,000) is considerably more expensive than the average out-of-state placement ($202,000).
- The higher costs of in-state placements often obliterate much - if not all - of the financial savings to be gained from Medicaid reimbursement.
- Medicaid reimbursement extends only to the services - and not the room and board - component of a placement, such that only a percentage of each placement is reimbursable.

- Many of the restrictions encumbering DDD's ability to receive Medicaid reimbursement for current out-of-state placements are self-imposed (and not mandated by the federal government).

- DDD is compelling the relocation of out-of-state residents whose placements are already receiving Medicaid reimbursement.

- DDD is intentionally marginalizing families during the RHNJ process - by creating ELPs without family input, scheduling M&Gs without notifying families, refusing to reschedule M&Gs when family emergencies (such as deaths and hospitalizations) arise, etc.

- A disabled resident's presence out-of-state does not affect his/her NJ residency, as residency requires a legal state of mind that disabled individuals are incapable of forming.

Nelson Mandela once said that "…there can be no keener revelation of a society's soul than the way in which it treats its children." As the mother of four young children - but *especially* as the sister of child trapped in an adult body - I couldn't agree more. I can only hope that you are similarly inclined and will do what you can to stop - once and for all - the inhumanity of RHNJ. NJ's disabled out-of-state residents deserve better.

Thank you for your time and interest today.

Very truly yours,

Carolyn Purcell Reichenbach

Testimony Before the New Jersey Senate Legislative Oversight Committee on New Jersey's Return Home Policy

Theodore Kastner MD, MS

Professor of Pediatrics
Ruth L. Gottesman Chair in Developmental Pediatrics
Co-Director, Rose F. Kennedy Center
Chief, Division of Developmental Medicine,
Albert Einstein College of Medicine

President, Developmental Disabilities Health Alliance
1285 Broad Street
Bloomfield, New Jersey 07003

June 10, 2015

Senators Gordon, Weinberg, Kean, Kyrillos, Ruiz, Sarlo and invited guests, I am honored to have the opportunity to testify before you today at this meeting of the New Jersey State Senate Legislative Oversight Committee.

My name is Theodore Kastner, MD, MS and I am a Professor of Pediatrics at the Albert Einstein College of Medicine where I hold the Ruth L. Gottesman Chair in Developmental Pediatrics and serve as the Co-Director of the Rose F. Kennedy Center and Chief of the Division of Developmental Medicine. In thiese roles I supervise the provision of services to more than 7,500 individuals and families with intellectual and developmental disabilities by a staff of approximately 170 professionals. I oversee two large federal training grants and a robust research program. I am also the Director of our University Center on Excellence in Developmental Disabilities and sit on the New York State Developmental Disabilities Planning Council.

I am also the President of Developmental Disabilities Health Alliance, the largest provider of health care and mental health care services to persons with developmental and intellectual disabilities in New Jersey. I have been a Medicaid provider serving this population for nearly 30 years. Over the past 18 years our organization has provided primary care and mental health services to nearly 10,000 patients – about 25% of all individuals served by NJDDD persons with intellectual and developmental disabilities who live in the community. In 2010 alone, we served more than 6,000 unduplicated clients of NJDDD and United Health Care before our contract with United was terminated.

Our organization currently operates 5 primary care/mental health practice locations for persons with intellectual and developmental disabilities across the State – stretching from Bergen, Essex, Middlesex, Ocean and Camden Counties. We currently serve more than 1400 people with intellectual and developmental disabilities including more than 900 with mental illness. Given that we are one of the few practices specializing in the care and treatment of persons with IDD and accepting new patients, we have been swamped with new referrals as a result of the Return Home and Olmstead programs. Over the past two years we have provided primary care and/or mental health services to at least 74 persons with intellectual and developmental disabilities who are enrolled in the NJ Return Home and/or Olmstead programs. I believe that we are the largest provider of health care services to this group in the State.

However, we receive no significant compensation from Medicaid HMOs for our services. At the present time we do not contract with Horizon NJ Health, United HealthCare, Amerigroup or Aetna. Our funding is obtained mainly through a cooperative agreement with the Centers for Medicare and Medicaid Services (CMS) which will end on

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December 31, 2015. At this moment I cannot tell you whether we will be providing any services after December. We expect to close our Hackensack office in the fall and are planning for the potential closure of at least two other locations. We can't continue to provide free services on behalf of Medicaid HMOs.

I am here to discuss how persons with intellectual and developmental disabilities who participate in the New Jersey Return Home and Olmstead programs obtain health care services once they are relocated to the community. In doing so, I will discuss the role of NJ Medicaid and Medicaid HMOs in paying for health care services for this vulnerable population.

<u>The Role of NJ Medicaid:</u>
As you know, all clients of the NJ Division of Developmental Disabilities are now required to be eligible for Medicaid. In addition, all persons with intellectual and developmental disabilities in New Jersey who receive Medicaid are now required to be enrolled in a Medicaid HMO where they receive all of their primary care, mental health and dental services in addition to their pharmaceuticals, durable medical equipment, disposables such as diapers, home health services and medical day care. All individuals who participate in the New Jersey Return Home and Olmstead programs receive their health care services through Medicaid HMOs. As a result, understanding the role of Medicaid and Medicaid HMOs is critical in recognizing the barriers to accessing appropriate health care services for persons with intellectual and developmental disabilities served through New Jersey Return Home and Olmstead.

<u>The Role of Medicaid HMOs:</u>
The role of Medicaid HMOs in providing health care services to persons with intellectual and developmental disabilities is defined in the contract between Medicaid HMOs and the State of New Jersey which can be accessed at:

http://www.state.nj.us/humanservices/dmahs/info/resources/care/hmo-contract.pdf

According to the contract, NJ Medicaid HMOs are responsible for at least four distinct deliverables. These include the following:

(1) Maintaining a specialized network of providers who will deliver both physical as well as MH/SA services. The specialized provider network shall consist of credentialed providers for physical health and MH/SA services, who have experience and expertise in treating adult clients of DDD and children who were transitioned from DDD to DCF who have both physical health and MH/SA needs, and who can provide internal management of the complex care needs of these enrollees. The Contractor shall ensure

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that the specialized provider network will be able to deliver identified physical health and MH/SA outcomes.

(2) Providing a program of medical management services for adult clients of DDD and children who were transitioned from DDD to DCF, which shall include Care Management which includes a Comprehensive Needs Assessment, development and implementation of a Care Plan, referral, coordination of care, continuity of care, monitoring, and follow-up and documentation.

(3) Implementing Quality improvement techniques/protocols to effect improved quality of life outcomes.

(4) Designing and implementing clinical pathways and practice guidelines that will produce overall quality outcomes for specific diseases/conditions identified in adult clients of DDD and children who were transitioned from DDD to DCF. (HMO Contract Section 4.5.3)

In our experience, NJ Medicaid HMOs do not meet any of the four criteria set forth in their contract. The result is that individuals with intellectual and developmental disabilities who participate in the NJ Return Home and Olmstead programs receive inadequate health care services.

Access to Care:

The primary measure of network adequacy is access to care and it is no secret that New Jersey ranks last, by a wide margin, among all states in regard to access to Medicaid services. In a study published in 2013 in the prestigious journal *Health Affairs*, Decker examined the rate of physicians willing to accept new Medicaid patients. Nationally, about 33 percent of primary care physicians (meaning those in general and family medicine, internal medicine, or pediatrics) did not accept new Medicaid patients in 2011–12. The rate varied from a low of 8.9 percent in Minnesota to a high of 54.0 percent in New Jersey. As a point of reference, which California ranked second worst, with 46.3 percent of primary care physicians not accepting new Medicaid patients – about 8% better than New Jersey. A similar pattern exists for specialty physicians. About 27 percent of specialist physicians (including psychiatrists, dentists and other specialists) did not accept new Medicaid patients in 2011–12. The rate varied from a low of 4.1 percent in Minnesota to a high of 56.5 percent in New Jersey. As a point of reference, California ranked second worst with 44.8 percent of primary care physicians not accepting new Medicaid patients - a 12% higher rate of acceptance than New Jersey.

This data has been in the public eye for more than two years and yet the Administration has failed to respond. The legislature should require that NJ's health care system provide at least average access and that NJ Medicaid HMOs ensure that no less than 66% of physicians in NJ accept new Medicaid patients.

As noted above, NJ Medicaid HMOs are responsible for ensuring access to a "specialized provider network (shall) consist(ing) of credentialed providers for physical health and MH/SA services, who have experience and expertise in treating adult clients of DDD and children who were transitioned from DDD to DCF who have both physical health and MH/SA needs specialized network of providers." Further, NJ Medicaid lacks criteria for measuring whether Medicaid HMOs comply with this requirement. NJ Medicaid HMOs survey physicians as to their ability to serve individuals with "special needs" but individuals with special needs are quite different than persons with intellectual and developmental disabilities. In our experience, no NJ Medicaid plan operates a network which would remotely address this contractual obligation.

The legislature should develop specific criteria which can be used to measure network adequacy for persons with intellectual and developmental disabilities and require that NJ Medicaid HMOs meet these criteria. These criteria should include access to trained and experienced specialists in intellectual and developmental disabilities including practitioners in developmental/behavioral pediatrics and neurodevelopmental disabilities, mental health providers, neurologists and dentists in every County.

Costs of Care:
NJ spends more than $10B on Medicaid. Of that amount, HMOs are permitted to retain up to 20%, more than $2B dollars, to spend on administrative costs and profits. We should be getting better value for our public funds. New York allows plans to retain only 15%. At the same time, New York maintains a vigorous managed care program. This morning I counted 22 plans providing Medicaid managed care in New York including many of the same Medicaid plans that participate in NJ – United Health Care, WellCare, and Amerigroup. **I recommend that the NJ Legislature cap administrative costs and profit, the Health Benefits Ratio (HBR), at 15%, as they do in New York, in order to ensure that an additional $500M is spent on health care services in New Jersey.**

No one knows how the remaining 80% of Medicaid funds, more than $8B, are spent in New Jersey – no one that is expect for NJ Medicaid managed care executives and NJ Medicaid officials. In 2010 we attempted to obtain claims data from NJ Medicaid but were told we could receive only utilization data. The claims portion, the data regarding how much money was actually spent on health care, is considered proprietary and will not be shared by NJ Medicaid with anyone, including qualified researchers such as ourselves. In the course of working on our CMS project we sought the assistance of the federal government in obtaining this data. NJ Medicaid does not submit cost data even to the federal government. It is truly remarkable that no one can give an accounting for more than $8B in public funds spent to support NJ's most vulnerable citizens.

Public accountability for more than $10B in Medicaid expenditures outweighs the proprietary interests of insurance companies which contract with New Jersey to provide Medicaid services. **I strongly support the "Out-of-network Consumer Protection, Transparency, Cost Containment and Accountability Act." However, the Act should be strengthened by removing language granting Medicaid HMOs exemption from making their cost data available to the public. There is nothing proprietary about such claims data when the names of contractors and payors are removed. Researchers such as ourselves should then be given free access to the data, in the same way that the federal government provides access to Medicare claims data.**

Of the data which we were able to collect and analyze, we reported extremely high rates of emergency room use – more than 6 emergency room visits per person per year. Hospital admission rates were equally high. Our practice has demonstrated an ability to reduce emergency room and hospitalization by nearly 70% when compared to the routine care offered by NJ Medicaid HMOs. Patients in our practice experienced approximately 2 emergency room visits per year. This number of high relative to national standards and probably reflects over use as a result of changes in direct care staff behavior related to the implementation of Danielle's Law. .

The point to this discussion is that there is an extraordinary amount of waste in the current system. Rates of ER and hospital use by persons with intellectual and developmental disabilities are 3 to 4 times higher than they should be. This issue could be addressed by the improvements in HMO network adequacy discussed above.

Patient Experience of Care:

Our patients, including those served in the NJ Return Home and Olmstead programs, are deeply dissatisfied with the quality of care they receive from Medicaid HMOs. Clients, families, guardians and agencies report that they are unable to find physicians and dentists who will serve them. They are unable to obtain pharmaceuticals which are vital to ensuring that medical conditions such as epilepsy and psychiatric disorders are appropriately treated. One of our patients was seen in the emergency room on 12 occasions, hospitalized 5 times and underwent two surgical procedures simply because

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his HMO refused to provide him with psychotropic medication which had been demonstrated to keep his symptoms in remission.

There are legitimate concerns about patients' access to health care services, the quality of the care they receive and their health outcomes. Since September 2014, 244 of our patients have submitted 320 complaints to the NJ Department of Banking and Insurance about their inability to access health care providers and care management services from Medicaid HMOs. For the purposes of this testimony, we conducted a survey of the 74 individuals served in our practice who are known to be participating in the Return Home and Olmstead programs. 31% complained about a lack of access to in-network providers. 28% complained about a lack of care management services. Most of these complaints were directed at Horizon NJ Health which refuses to pay practices like ourselves for any out-of-network services and whose members are unable to determine whether or not they receive any care management services at all. There were also significant concerns about the United network .

NJDDD Member Complaints Filed with the NJ Department of Banking and Insurance (DOBI)

	Horizon	United	Amerigroup	Total	
All DDHA Patients					1400
Network	244	56	20	320	23%
Care Management	244	12	6	262	19%
Return Home/Olmstead					74
Network	21	2	0	23	31%
Care Management	21	0	0	21	28%

There has been no meaningful response to these complaints. DOBI states that the complaints are sent to NJ Medicaid. However, the plans have not recruited the providers needed to address these complaints or compelled Horizon NJ Health to provide their members with care management services. New patients who are clients of NJDDD continue to come to our practice, about 15 to 20 per month, complaining that they have nowhere else to go for services. **I recommend that the oversight of NJ Medicaid HMOs be given to the Department of Banking and Insurance in order to ensure that all complaints are registered and investigated.**

Risk Aversion:

Medicaid HMOs cannot turn members away. However, insurers can reduce their risk by deliberately avoiding contracts with providers, such as ourselves and other providers of services to persons with intellectual and developmental disabilities, who provide services to patients at higher risk. It would be mere conjecture on my part to allege that NJ Medicaid HMOs engage in such practice except for the fact that explicit statements to this effect have been made public by senior Medicaid HMO executives.

In the fall of 2014, about 40 of us attended a meeting hosted by the NJ Health Care Quality Institute to welcome Jackie Cornell-Bechelli in her role as the newly appointed Director of Region 2 for the US Department of Human Services. During the Q&A, one health care provider from southern New Jersey stated that they were experiencing difficulty obtaining a contract with any Medicaid HMOs. Before the Director could respond, the President and CEO of one of the largest Medicaid HMOs in New Jersey stood up and stated that her plan could not contract with the provider because "your patients are too sick and it would bankrupt our company." It was no surprise that this behavior occurs. However, we were stunned that a senior executive would make such a public acknowledgment of the practice. The only question is, how will New Jersey public officials respond?

I hope that this testimony helps you understand the challenges faced by persons with intellectual and developmental disabilities in New Jersey, particularly those enrolled in the Return Home and Olmstead programs. I believe that with your support and the adoption of the specific recommendations I have made, we can improve the health and quality of life of individuals served in the Return Home and Olmstead programs during their challenging transition.

Thank you for the opportunity to appear before you and your consideration of these issues.

References:

Decker SL. “Two-Thirds Of Primary Care Physicians Accepted New Medicaid Patients In 2011-12: A Baseline To Measure Future Acceptance Rates.” *Health Affairs*, 32, no.7 (2013):1183-1187

New Jersey Medicaid HMO Contract accessed on 6/9/2015 at http://www.state.nj.us/humanservices/dmahs/info/resources/care/hmo-contract.pdf

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Appendix 1
New Jersey HMO Contract Language Related to Persons With I/DD

4.5.3 CLIENTS OF THE DIVISION OF DEVELOPMENTAL DISABILITIES

A. The Contractor shall provide all physical health services required by this contract as well as the MH/SA services (except partial care and partial hospitalization services) included in the Medicaid State Plan to enrollees who are adult clients of DDD and children who were transitioned from DDD to DCF. The Contractor shall include in its provider network a specialized network of providers who will deliver both physical as well as MH/SA services, except providers of partial care and partial hospitalization services, (in accordance with Medicaid program standards) to adult clients of DDD and children who were transitioned from DDD to DCF, and ensure continuity of care within that network. The Contractor shall be responsible for MH/SA services to clients of DDD until the behavioral health ASO is implemented.

B. The Contractor's specialized network shall provide medical management services for adult clients of DDD and children who were transitioned from DDD to DCF, which shall include:

1. Care Management, including Comprehensive Needs Assessment, development and implementation of a Care Plan, referral, coordination of care, continuity of care, monitoring, and follow-up and documentation.

2. Coordination of care across multi-disciplinary treatment teams to assist PCPs in identifying the providers within the network who will meet the specific needs and health care requirements of clients of DDD with both physical health and MH/SA needs and provide continuity of care with an identified provider who has an established relationship with the patient.

3. Quality improvement techniques/protocols to effect improved quality of life outcomes.

4. Design and implementation of clinical pathways and practice guidelines that will produce overall quality outcomes for specific diseases/conditions identified in adult clients of DDD and children who were transitioned from DDD to DCF.

5. Medical treatment.

C. The specialized provider network shall consist of credentialed providers for physical health and MH/SA services, who have experience and expertise in treating adult clients of DDD and children who were transitioned from DDD to DCF who have both physical health and MH/SA needs, and who can provide internal management of the complex care needs of these enrollees. The Contractor shall ensure that the specialized provider network will be able to deliver identified physical health and MH/SA outcomes.

D. Adult clients of DDD and children who were transferred from DDD to DCF, may, at their option, receive their physical health and/or MH/SA services from any qualified provider in the Contractor's network. They are not required to receive their services through the Contractor's specialized network.

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E. Individuals who are both DCP&P/DCF clients and clients of DDD shall receive MH/SA services through the Contractor's network.

June 10, 2015

Thank you Senator Gordon and the Committee for this opportunity.

One of the basic flaws with Return Home New Jersey (RHNJ) from its inception is that it has entirely ignored the obvious, negative and disruptive effects of uprooting individuals with severe disabilities from their appropriate, long-term, out-of-State placements with familiar surroundings and highly qualified caregivers—to what my son, and many others like him, is "home".

These effects are in fact contrary to some of the stated goals of RHNJ and it is vividly clear that the Division of Developmental Disabilities (DDD) is disregarding its own mission which is to have the individual exercise their right to make choices.

A primary goal of Return Home NJ is to return individuals to a "comparable or better setting in New Jersey that meets their needs..." However, due to many factors but especially budgetary constraints, the "community based homes" known as group homes, are simply not equipped to offer the one-to-one staff support or on-site medical services that are required to properly address the needs of my son, as well as many of the individuals with severe and multiple disabilities, in order for them to enjoy security and to have any meaningful quality of life in a safe environment.

Another stated goal is to return individuals to New Jersey to be "closer to family" which completely ignores our State's geography. Appropriate facilities in neighboring States, such as New York and Pennsylvania where my son lives just 20 minutes from our front door, are actually closer to some New Jersey families than an in-State NJ placement.

As of this date, we have attended 15 Meet and Greets with DDD staff and provider agencies with the intention of making proposals for NJ group homes for our 32 year old son Drew. Drew has successfully lived in a campus style setting at Woods Services in Langhorne, PA for almost 14 years. Contrary to the RHNJ slogans, not one of these agencies offer COMPARABLE OR BETTER staffing and services than he already has in his current placement nor have any been CLOSER to our home. In fact the offers for these proposed homes were two, three, and four times the distance from our home.

As a result of meningitis at the age of three, Drew is blind, profoundly developmentally disabled, with right side hemiplegia, and an uncontrolled seizure disorder. At this very moment our family is facing an offer of a group home which is 40 minutes from our home where he will have a staff ratio of 1:4 rather than the 1:1 ratio he presently has at Woods and requires to have any quality of life. That is one staff to four individuals for the major part of his day. My son needs to be fed and clothed, have his diapers changed and be guided by the arm or gait belt in order to safely navigate his environment.

Yet, just one month ago, on May 5, 2015 when Senator Van Drew asked Acting Commissioner Connelly and Asst Commissioner Apgar whether staff ratios in NJ group homes are equal to that of the out-of-State residences, they answered they are "better". That is amazing! They are either misinformed or unaware. And it is no wonder families are terrified of relocation when DDD is reducing and/or eliminating services and staff and it is no wonder that there are hundreds of cases of abuse and neglect reported each year because of it.

Senate President Sweeney is quoted as saying RHNJ should be "scrapped" in order to protect the innocent, vulnerable people who are living a safe, happy life in their out-of-State placements.

So the glaring question is why are we, who had to make the heart wrenching decision for a residential placement for our beloved sons and daughters many years ago, being pressured by DDD who is blindly moving forward with this flawed and inhumane relocation called Return Home NJ.

In conclusion, I want to say the real question is, at what number of years is it okay to remove someone from their "family and home", housemates, friends, teachers, nurses, doctors, therapists, and relocate them to a new untrained, understaffed "family and home"?

Do you really think that the relationships build in 5, 10, or 15 years are any less valuable than those made in 25 years?

We are desperately reaching out to you, our Legislators, to disregard the meager cost savings already admitted to by the Division and protect our family members from the inhumane consequences of RHNJ.

Thank you.

Marcia Adams

8 Wolfpack Court

Mercerville, NJ 08619

609-586-3250

Robyn Levine

First I would like to take the opportunity to thank the oversight committee for taking the time to hear my testimony regarding "Return Home New Jersey." Please understand that my story is not meant to be an attack on anyone, but share with you my experiences and concerns. Please understand that this legislation impacts my daughter, who I have spent the past 30 years advocating for, as she does not have a voice.

The state has implied that the purpose of "Return Home New Jersey" is logical and has the best interest of our loved ones at heart. However, having a child who has already been placed in her home thirteen years ago and is now a part of this unorganized and horrifying process, I can firmly provide you with reasons why this policy is not financially, medically, or morally sound. If there was ever a time for the legislative representatives to step in and protect its constituents, that time is now!

On June 12, 2014 DDD stated that one of the reasons Return Home New Jersey is so important is, and I quote, "significant uncertainties about our ability to adequately monitor the care and well-being of individuals in out-of-state programs." I truly appreciate the care and concern that the state claims they have for my child; however, thirteen years ago my daughter was placed by DDD into her current home because they firmly agreed that there was not one facility in NJ that could care for her. Never has any member from the state come to check in or "monitor" my daughter. Up until this point, all communication has only ever been done over the phone. I am confident that not one member of DDD has ever met my child, including her case manager. How could DDD claim that they know the best care for my child if they have never even met her?

The state also vocalized, "New Jersey has concentrated on returning out-of-state NJ residents to in-state placements in order to more closely monitor their care and safety –as well as to bring them into a network of care that is closer to their families."

Unfortunately, my experience has been the complete opposite of this stance. Since nine years of age, my daughter has required a one-on-one in whatever program she has participated in, and we have a current letter from a neurologist stating that my daughter requires a one-on-one assistance at all times. Yet, DDD has informed me that they will not guarantee a one-on-one if she is brought home. Also, my daughter currently resides in a home where there are eight staff members for seven kids; yet, every agency that DDD has suggested has had a lesser staff to child ratio, often with the LPN serving as a care taker. Locations for the suggested homes have been in unsafe towns, on busy streets, with much less monitoring then what my child is receiving now. As for the comment regarding "closer to families," unfortunately this has not been true. DDD claimed they wanted parent input, so all families of the Return Home victims were asked to create ELPS to help the agency better understand the needs of our children/siblings. Yet, there has been a total disregard for this. We religiously visit our daughter a minimum of two times a week, so it was very important to me that she be no more than an hour away, like she is currently –yet suggested placements have been over three hours away one way. How is this bringing my daughter closer to her family?

I have been told that if I do not agree to Meet and Greets even though I know that the home is not a good match for my daughter, I can be viewed as being non-compliant and my daughter's funding will be removed. After several meet and greets, the response seems to be the same, "We can NOT provide for Ashley. We do NOT have the services that Ashley needs. We would have to request MORE money from the state in order to discuss being able to accommodate Ashley."

I question if this isn't truly about the money by returning home the already "home" residents, then why hasn't DDD worked to place those who are desperately in need on the waiting list? I am confident that the funds that would be needed to accommodate my daughter and many of the others would be just as great if not greater in NJ. DDD has shared their fee for services, so it is not difficult to add up all the services that are provided and see the cost per child/adult. What anyone is failing to share is that to keep costs down, our loved ones are being returned home and not provided the equal services they are receiving now. Use my daughter's one-on-one for example. DDD is clearly not worried about her safety or medical fragility by ripping away the only life line she has. If returned home and given the services she has now, the cost for her to reside in New Jersey would be GREATER than the current cost.

DDD was created to protect and serve as advocates for the disabled population. So I ask, why has DDD created a "one size fits all policy" when they are supposed to be the experts and know that people with disabilities require individual modifications, accommodations, and needs? The idea of returning home for some may be feasible, but for many it is not. New Jersey should not be forcing families to take their severely disabled and placing them in a home that may or may not work, and when posed the question what would happen if our loved ones were brought home and the home does not work, DDDs response, "We have to look into it." Yet, the truth is how can the state approve legislation that is not logical or completely and utterly thought out.

It is also extremely important to address the idea that the state claims that places like my daughter's home and many of the facilities that our loved ones are currently at, are not good because the residents are not integrated within the community and therefore are being institutionalized. This statement is not only false, but does not address the need for sensitivity to the severely disabled. I do not need my daughter gawked at, mocked, or made fun of because the world around her fears the unknown. My child is safe and comfortable. She has friends, attended a prom, and has gone to concerts and events. My child is in a community, and the state has no right to say otherwise. Just like other children and adults choose friends with similar interests and lifestyles, our loved ones should have that right as well.

Please remember the pawns in this match are PEOPLE, people that need the most support and help. For an agency that was created to advocate for people with disabilities, all they are doing is putting the lives of the disabled at risk.

~~and others that at DDD~~

~~DDD~~. Dawn Apgar makes the process sound reasonable, but that's not been our experience.

← tonight

Susan Henoch

Thank you for this opportunity to speak with you frankly about our experience with DDD and its Return Home New Jersey policy. I am here today because ~~DDD's RHNJ~~ this policy makes no common sense: It doesn't respect the complicated needs of our adult children ~~or siblings~~ with developmental disabilities and the love and concern we have for them. ~~(I grew up in New Jersey and am an alumna of Rutgers Law School, Newark. Along with my husband, who was also born and raised in New Jersey,)~~ **I am the parent and legal guardian of a 27 year old daughter** Sophie **who was born with Prader-Willi Syndrome, a rare and complex genetic disorder which occurs in one out of approximately 25,000 live births. Without a functioning hypothalamus or endocrine system, she has a long list of symptoms including low muscle tone, cognitive disabilities, severe behavioral issues and most importantly, chronic feelings of insatiable hunger that can lead to excessive eating and morbid obesity unless externally controlled. She requires 24 hour care** to prevent access to food. She requires 1:1 staffing at all times to monitor this behavior, ~~especially when she is out in the community, where she steals food and other items if left unattended even for a moment~~. She ~~also~~ has psychiatric diagnoses related to defiance and anxiety. **She suffers frequent meltdowns, more than one hundred this past year requiring physical restraint. She becomes verbally abusive and physically aggressive toward staff and other residents, punching, scratching and biting with the intention to inflict injury—and she often does. She poses a danger to herself and others and requires 3 or 4:1 staffing to ensure her own and others' safety. She also often threatens suicide.**

It never occurred to us to send her away from our home and family until her increasingly violent behavior and life-threatening weight gain overwhelmed our ability to care for her. She was 17 and DDD, recognizing we were in crisis, helped us find a nearby out-of-State placement, so we could visit her and she could come home at ~~some~~times. Unfortunately, she was housed with a group of girls with a variety of disabilities and without proper supervision, she gained weight; ~~after less than six months, she~~ then was abused by staff and suffered a psychotic break. We ~~rescued her immediately and~~ took her home to recover under the care of a psychiatrist. and Several months later, DDD agreed that the best placement for her was the one recommended by PWS medical and psychiatric experts, **an intensive therapeutic program in Wisconsin, where she has thrived for the past nine years. It has been dedicated to the care of people with PWS for over thirty five years and currently addresses the needs of nearly one hundred people with with the most difficult medical and behavioral PWS needs, three quarters of whom come from all over the country, at a cost that is half (or less) of New Jersey providers. She lives in one of a number of group homes located in several small country towns with a diverse group of PWS housemates-men and women of different ages, ethnicities and backgrounds. All of the services and supports she requires to function, including daily sessions with the on-site social worker, as well as a nurse, nutritionist, psychiatrist, art therapist and physical fitness instructor, among others, are wrapped into her program.** When she first arrived, she was dangerously obese, 235 pounds at 5' tall; since then, due to consistent knowledgable care, she has lost nearly one hundred pounds and now maintains a healthy weight. Please note that without this level of care, she would rapidly return to a life-threatening level of obesity.

1/3 of her life.

She works full-time in a sheltered workshop and with the 1:1 supervision of a job coach, volunteers at a retirement home where she gains job skills working with the residents. She feels respected and part of the world of work, earning her own wages. She is a member of the program's Special Olympics teams every season. She has long-term friends and staff she loves and who care for her. She is embedded in her life at PWHO, living as fully and independently as she is capable; she is a member of a vibrant PWS

community and the larger community, where she visits the library, goes on walks and coffee and ice cream outings with her housemates and staff. We visit her every other month and speak with her every day. **Most importantly, she is safe and healthy and happy- and we know she is receiving the care she needs.**

This should be the end of the story, as nine years ago, DDD did the right thing in placing Sophie in the correct program where she is thriving. But several years ago, we received a shocking letter from DDD informing us that it was cutting her funding and relocating her to New Jersey. If we wanted her to remain in place, the letter stated, we could either pay for her ourselves (not possible) or apply to have her residency changed to Wisconsin, (in which case she would go to end of their waiting list for services). Why disrupt her now? Why show such contempt, lack of understanding and blatant indifference to those same needs now? If it's about the money, the Commissioner of Human Services admitted recently there are no cost savings due to RHNJ. It is incomprehensible if based on what's in ~~her~~ Sophie's best interest. Despite DDD's supposed commitment to having families involved in the process and in 100% agreement with any eventual placement, DDD has chosen an adversarial approach instead from the beginning —and things have only gotten worse. RHNJ staff shamelessly exploit their position to intimidate families by the inherent imbalance of power. Using only slightly veiled language, they make it clear that parents do not have a right to reject an offer with impunity, whether or not the potential program can provide the level of care our children need. All of us have been warned that our children's funding can be cut at any time, particularly if we "do not cooperate", however DDD defines that. We are treated without equal status in this process, with a strong sense of threat hanging over us at all times.

Return Home New Jersey is clearly not based on common sense. There is no process and what little protocol exists changes at the whim of DDD without notice. I have been forced to hold conversations with seven directors of potential programs, most of whom had never even heard of PWS. The only one who had rejected my daughter outright due to her violent behavior. Another one was part of a real estate firm that and knew nothing. Yet another made sure I understood they respected disability rights and then proceeded to describe a program that would put her life at risk in the home daily. During my most recent conversation several weeks ago, a program director stated that her nurse was looking it up on the internet as we spoke. This program's founder was recently indicted by the federal and New York State governments for Medicaid fraud, had its license revoked by the State of Pennsylvania for numerous violations and nearly killed a young autistic resident at one of their NYC group homes. The director of another program, the one most highly recommended by RHNJ Director Conger as the best and only one in the State able to meet my daughter's needs, stated that the extent of his knowledge was what he had just read on three websites on the internet, but otherwise his agency had no history, experience or training to work with the PWS population nor any program, staff, work opportunities, social work or psychiatric services in place. This agency also has a long, sordid history of abuse and neglect of clients in multiple states since it was founded in 1968. It relies on the use of mechanical restraints and a behavior therapy model that would be totally ineffective in treating my daughter. **DDD has done its best to mischaracterize us as afraid of the future, of change, but what we're actually afraid of is DDD's attempt to endanger our ~~daughter's life~~ children's lives by tearing ~~her~~ them away from ~~her~~ their current successful life to live in a four woman isolated group home run by an inexperienced provider without organized full-time work or access to the supports and services she requires. What is the point?**

Even the assessment tool "Return Home New Jersey" uses to determine my daughter's needs, the "ELP Learning Community" document is inaccurate for this purpose, asking irrelevant questions while omitting more important ones; it does not even elicit the information that could assist a potential provider to understand the full scope of Sophie's needs in order to determine whether they can meet them, rather than wasting everyone's time.

Then there's the issue of Danielle's Law in New Jersey: Assistant Commissioner Apgar agreed with me during a recent conversation that my daughter's life is at risk because of Danielle's Law which requires staff "to call 911 in any life threatening emergency, which includes "any escalated behavior where a person is a danger to him/herself or to others (if verbal and Crisis Management techniques have failed and you are unable to use Crisis Management Techniques to de-escalate the behavior safely) and in cases of "suicide threats…" Sophie fits both criteria. It takes years of experience and on-going training to know how to handle PWS effectively, especially with people who have extreme behaviors, such as Sophie. Since the potential providers with whom I spoke did not understand even the basics of PWS or have experience working with the PWS population, they would automatically put her at risk. As in the case of Tyler Loftus and others, if staff are insufficiently trained to restrain her safely and call 911 for assistance, bringing in untrained strangers to restrain her by any means they deem necessary, there is the potential they would kill her in the process, by employing the wrong technique or escalating her agitation to the point of precipitating another psychotic break. Sophie would more than likely end up in the same cycle as Tyler, forced out of placements, in and out of emergency rooms, hospitalizations, even jail and emergency placements, because there is no program in New Jersey with the experience, training and staff who are adept and comfortable dealing with PWS behavioral issues.

So, who does RHNJ serve? It endangers the most vulnerable of lives, those of our developmentally disabled citizens, our children, who have no voice of their own to advocate for themselves. It requires administrators and caseworkers to abrogate the most basic principle of their training by acting against the best interests of their clients. It pits the Division of Developmental Disabilities against families, instead of working together to "assure the opportunity for individuals with developmental disabilities to receive quality services and supports, participate meaningfully in their communities and exercise their right to make choices", as their own Mission Statement pledges.

I love my daughter with all my heart and will do whatever it takes to keep her alive and safe and healthy. I have always advocated and fought for her right to live as full a life as possible. Nine years ago, the State of New Jersey understood this principle, as well, and did the right thing when they placed her in her current home and community; we ask you to honor that decision, to help us keep her alive and safe, by allowing her to remain where she is, already home in the one place she belongs.

June 10, 2015

Senate Oversight Committee Members
The Honorable Senator Gordon, Chairman

Re: Stop RHNJ

Dear Senators:

Hello, my name is Maureen Clark. I am here today to beg you to quickly pass a bill to stop the inhumane DDD Return Home NJ program. We need action now. PLEASE. Our daughter needs to stay at Woods, in Langhorne, PA, less than 10 miles from Trenton, where she has lived for 36 years. How can anyone with any degree of compassion feel that it is okay to uproot her at this stage of her life?

We are very frightened because we have been notified by DDD that we have to tour a 60 bed Intermediate Care Facility (ICF), which is a cross between a hospital and a nursing home. While the care may be adequate, why would DDD place her in a more restrictive environment than she has enjoyed for 36 years? DDD is proselytizing community living, so why would they take her from her ranch-style home with 11 other ladies on a scenic campus and put her in a hospital-like setting?

Will DDD move her again when they decide the ICF is too restrictive and decide ICFs are wrong? Actually, DDD continues to push four-person group homes, so it is a matter of time before they close down the ICF. What will they do with our daughter then? To date no group home has agreed to take Maura because of the care she needs, and they say the DDRT funding is inadequate. What happens to Maura then?

Why isn't the bed being offered to one of the 6,000 disabled individuals on the waiting list. There are many elderly parents begging for a placement.

It is all about money, we know. But even Acting Commissioner Connolly stated at the Assembly Budget Hearing on April 20th that they could not determine if there has been any cost savings by uprooting the disabled. The Office of Legislative Services was also unable to determine if there would be any cost savings.

We are perplexed why DDD refuses to qualify a facility like Woods when Federal Medicaid would allow it. Maura, and many like her, are the victims of a one-size-fits-all policy. Federal Medicaid requires that the individual have a choice of setting options. DDD is disregarding this requirement. Federal Medicaid requires the individual receive necessary services in the setting that best fits their needs. Federal Medicaid does not prohibit site-specific settings like a campus-style facility. Nor does it stipulate the size of the residences. Federal Medicaid will reimburse for care in PA.

Federal Medicaid does not cover room and board; therefore there will be less than the 50% reimbursement that DDD claims. (Per OLS Fiscal Estimate of Bill S2249, July 3, 2014.) Why won't NJ qualify Woods for the Community Care Waiver? Why is their policy more stringent than federal requirements?

Our 48-year old daughter Maura has been at Woods in Langhorne PA for 36 years this month. She is severely intellectually and physically disabled with Cerebral Palsy and spastic quadriplegia. She cannot walk, speak or feed herself and she has uncontrollable seizures that are exacerbated by change. Maura is medically fragile. Besides the seizures, the nurses continue to check for osteomyelitis both on her foot and her buttocks, as well as for aspiration pneumonia.

Maura is completely dependent on caregivers for every aspect of her life. However she is not a vegetable or a piece of furniture to be moved around. She has likes and dislikes and has strong wardrobe preferences. She loves most of the Sesame Street characters. She is uncomfortable with strangers. She is receiving excellent care at Woods, a campus-style community. She receives needed 24-hour a day nursing, medical support, a day program and physical therapy. It is important to note that the medical specialists on campus have the expertise derived from overseeing the care of many individuals with complicated medical issues. They know Maura, and have been treating her for 36 years. At Woods, Maura has security, consistency, a home and staff who love her. She has many friends in her house and day program.

She enjoys many recreational activities both on the campus and in town. Maura is very happy there and loves her caregivers and many friends. She is part of a beautiful family at her ranch-style residence on the campus. And best of all, Maura is not in an institutional or hospital setting. She is part of a community already. At her home in Woods, Maura shares a house with ladies of varying levels of intellectual and physical disabilities. Although she cannot speak, others can, so there is plenty of interaction and laughter. Moving Maura will not give her more independence. On the contrary, it will deprive her of the few joys she has in life.

I am asking you to protect Maura and others like her. The RHNJ forced move may have been motivated with good intentions, but it is ill conceived and lacks real life knowledge about the needs of the disabled and the true cost of their care.

Sincerely,

Arthur and Maureen Clark
Sparta, NJ 07871

RETURN HOME NJ

CONSEQUENCES FOR MY DAUGHTER,

ALEXA R. KELLY

- LOSS OF CLINICIANS: NURSING, DIETICIAN, SP, OT, & PT WHO SUPPORTED THE DIRECT CARE STAFF.
- GROUP HOME DIRECT CARE STAFF ARE MINIMALLY TRAINED AND POORLY EDUCATED SOME STAFF UNABLE TO READ AT A HIGH SCHOOL LEVEL, INCLUDING MANAGERS. EDUCATIONAL REQUIREMENT TO WORK IN A GROUP HOME IS A HIGH SCHOOL DIPLOMA OR EQUIVALENCY.
- LACK OF SUPERVISION OF DIRECT CARE STAFF BY MANAGEMENT, ESPECIALLY ON WEEKENDS.
- EXTREMELY HIGH TURNOVER RATE OF DIRECT CARE STAFF AND HOUSE MANAGERS. IN THE PAST YEAR MY DAUGHTER HAS OVER 40 DIRECT CARE STAFF AND 4 HOUSE MANAGERS.
- LACK KNOWLEDGE IN DIETARY MANAGEMENT, ESPECIALLY WITH RESTRICTED DIETS.
- NO TRAINING IN PLANNING AND PREPARING SAFE NUTRITIOUS MEALS.
- NO CONSEQUENCES TO COMMUNITY CARE PROVIDERS FOR NEGLIGENCE. ALEXA'S GROUP HAS YET TO PASS A STATE INSPECTION IN THE 2 YEARS IT HAS BEEN OPEN BUT ABLE TO GAIN FULL LICENSE STATUS.
- 2 HOSPITALIZATIONS FOR ASPIRATION PNEUMONIA DUE TO CHOKING EVENTS.
- NUMEROUS MEDICTION ERRORS INCLUDING SEIZURE MEDS.
- MISSING MEDICATIONS
- INACCURATE MEDICAL RECORDS, INCLUDING EMERGENCY RECORDS AND MEDICATION ADMINISTRATION RECORDS
- NO COMMUNITY OUTINGS OR RECREATIONAL ACTIVITES

My severely disabled daughter was removed from Woods Services due to RHNJ and placed in a group home a year ago. This has not gone well for her. She has been hospitalized twice with aspiration pneumonia due to choking events. There have been numerous medication errors, missing medication, falsification of medication administration records to cover up the missing meds. Her one and only community outing she has experienced with the group home this past year, involved spending two and a half hours in the car while staff went shopping. In addition, her staff neglected to bring her emergency seizure medication with them. In another incident she was taken to the ER without family being promptly notified, and with no medical records. She is fed excessive amounts of junk food, which caused her to gain 10 pounds within the first 8 weeks of her arrival in the home. She is supposed to be on a restricted diet due to Inflammatory Bowel Disease. I now provide the majority of her meals because following her diet has proven to be impossible task for staff handle.There have been more than *forty* different direct care staff she has had to cope with over the past year including 4 managers, dressing, feeding and bathing her. Talk about anxiety provoking. How would like a total stranger in your bathroom each week assisting you? The agency is now looking for manager number 5. This is just a sample of the many problems she has encountered. This placement has left me unable to sleep. I feel anxiety ridden all of the time. I have spent countless hours writing letters to DDD and DHS and the agency who provides her care/ Community Options. The majority of the time I get no response from anyone. I had a five minute private conversation with Governor Christie, in which he took my name and number on his business card and said he would have the DHS commissioner contact me the next day, that didn't happen. Instead, I got to spend the next ten days calling the constituent's office and bothering a lovely young woman, the liaison for DHS. I finally get my conference call with Beth Connolly and Dawn Apgar, only to be informed by Ms.Apgar that she has no control over the agency that provides my daughter's care and felt my daughter was not in a safe placement. Her recommendation, that Alexa move to another agency. Ms. Apgar's statement left both me and my daughter's attorney dumbfounded. We retained an attorney for my daughter due to all the very serious, significant problems, Maria Fischer, so she too was on the call. She reminded Ms. Apgar that DHS supplies all the funding, licensing, and clients for agencies in order to do business, so they definitely have a say in how agencies conduct business, it's called regulations. But I guess Ms. Apgar is right. My daughter's group home has yet to pass an inspection in the two years it has been opened. They even failed implementation of their plan of correction, yet were still able to attain full license status. I inquired to the licensing and inspections agency how this can be, only to be informed by an agency employee, that my daughter's group home was not that bad and I should some of the other inspection reports! I am providing each you your own set of inspection reports to my daughter's group home so you can see for yourself. I guess Governor Christie has no control in any of this either.

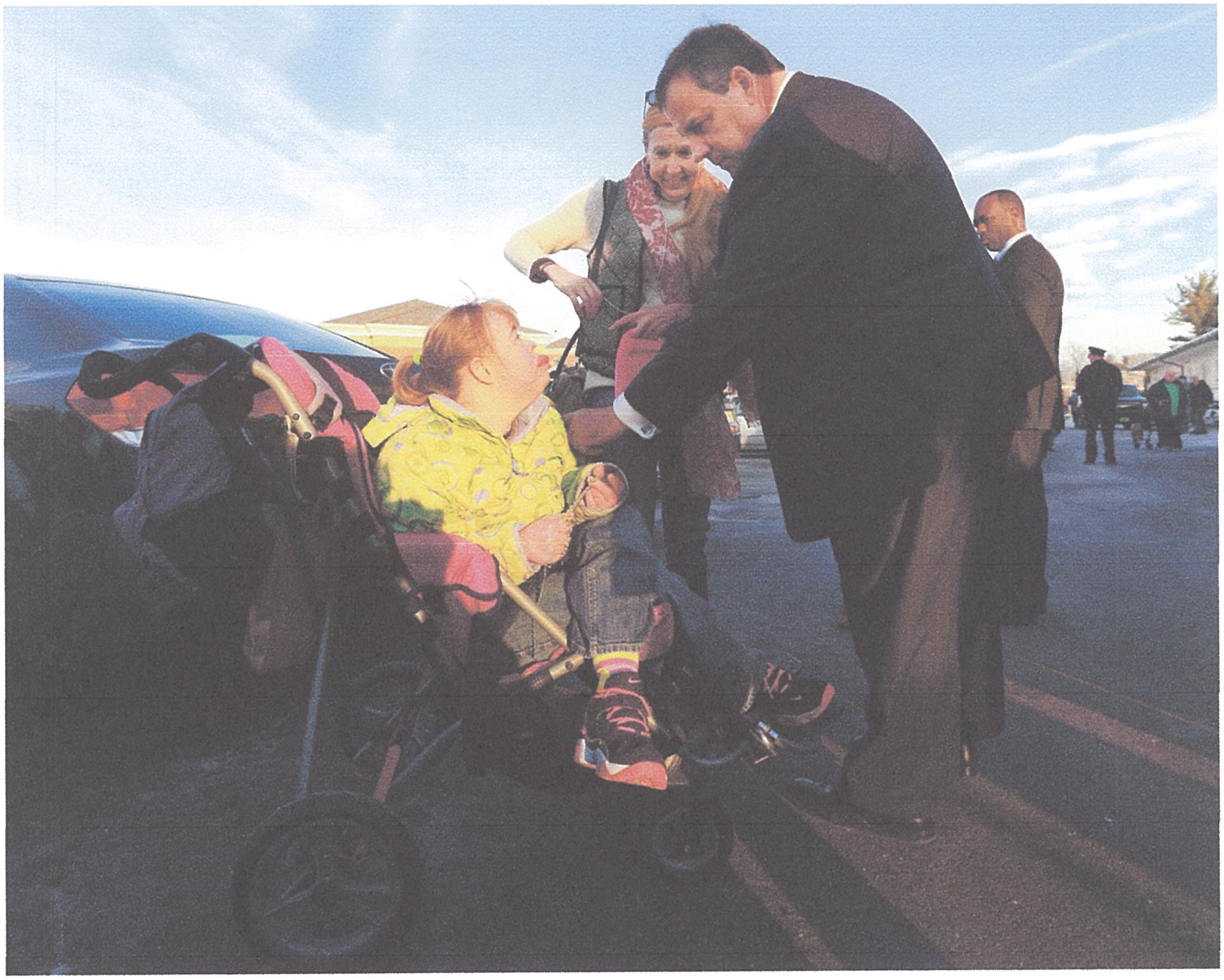
So what happens when you can't take the stress of all this anymore and you get angry with the agency and DDD and start taking pictures of some problems, like not having adequate food to follow a medical prescribe diet. You get kicked out. This is what happen to one my daughter's housemate's family. They where not allowed into the group home for 3 months. It didn't matter the agency was violating the client's rights by not allowing her family to come visit her and DDD was absolutely no help to family in getting it resolved. They had to hire an attorney too.

I am MAD! DDD removed my daughter from a very stable situation and put her life in peril. I have been begging the DHS and DDD commissioners to have my daughter reassess with the new NJCAT to no avail. I believe her budget would increased and this could help provide the supports she needs to be in the community. If any of you could help me achieve this I would be most grateful to you.

This is a very broken system. The direct care staff are not qualified to be doing this type of work. The majority of the time when they are caring for clients, there is no oversight by management, especially on weekends. The only requirement for direct care staff positions, including the house manager, is a high school diploma or equivalency. I question if some staff even possess those credentials, as I find some are unable to read or write at a high school level, including the managers. I have great admiration, respect, and deep gratitude for the people who go into this field. The majority of them are caring women, who have not had many opportunities in life. They are willing to accept poverty wages for hard, challenging work. They are minimally trained and poorly educated. They have to deal with all sorts of challenges with clients. They contend with medical responsibilities and behavioral issues, as well as being accountable for all aspects of running a household, including meal planning and preparation. Most direct care staff hold down two jobs, and some even have three. They live on cheap fast food due to the time constraints of working 2 or 3 jobs, so they have no idea how to prepare menus or safely prepare and cook nutritious meals. If a client has a restricted diet, like that of my daughter's, it will not be maintained. The majority of the time, clients are fed junk food such as frozen pizza, chicken nuggets, french fries, and mac and cheese. No wonder my daughter gained 10 pounds in 8 weeks! That kind of rapid weight gain puts her on track for even more ailments, such as diabetes. Do you realize that to cut hair for a living in New Jersey, you have to receive **TWELVE HUNDRED** hours of training in a certified program in order to obtain your license? But to administer powerful drugs, provide nutritious meals, and maintain the hygiene, safety, and security of individuals with developmental disabilities, you just need to pass a criminal background check and not have a DUI in the past two years. This is a CRIME! As for utilizing community resources, the community is not ready! The local ER is not prepared to be used as a clinic for this population. My daughter now has a protocol in place for every time she vomits; 911 must be called due to her first hospitalization because she was left unattended while vomiting in her bed. ER doctors do not know the right questions to ask of staff regarding medical consents and guardianship. I personally educated two community hospitals in our area so they know to call me if my daughter shows up there without me and to inquire about guardianship and medical consent forms for the patient they are treating. The ER cannot rely on the direct care staff present because they may not have records with them and if do they probably won't be correct. I have provided an "in case of emergency" information document about my daughter to the local EMS. This ensures that if a 911 call is made, they have the correct medical and contact information. I cannot trust the agency/Community Options to provide this information. Management has sent a client to the hospital from this group home without staff or records, and took my daughter to the ER without her medical records and was not even able to even provide my daughter's correct weight to the nurse. Staff overestimated by 50lbs! The agency is suppose to be able to handle all her medical care and get her to all her medical appointments. This has been completely impossible for the them to handle due to total incompetency and the never ending shortage of staff. They can't even provide familiar staff to care for her when she is unable go to day program due to seizures or illness.

There have been numerous incident reports in regards to my daughter. DDD is the decider if they need to be investigated by the Office of Investigations. Talk about the fox guarding the hen house! DDD and the community providers are too intertwined with each other for this policy. There is too much opportunity for corruption to occur since the providers need clients, and DDD needs placements. Even when the Office of Investigations gets involved, they are supposed to wrap up an investigation within 60 days. My daughter's first hospitalization took 10 months , the second hospitalization took 7 months for the investigations to be finalized. Unsubstantiated neglect, no surprise there.

Clearly, there is a lot of money involved here. I find the agencies are in the driver's seat. I have overheard phone conversations between the agency and DDD asking for payment for services rendered, only to discover that New Jersey is one of the worst states for reimbursing their service providers. So what does that mean? It means that when a group home is poorly run, like the one my daughter is in, what is the state going to do about it? Fine them? No, you don't pay them. Take away their license, you have no place to put clients. The state will do NOTHING! The agency providing my daughter's care /Community Options seems to be doing very well with this type of arrangement. So much so, they may be the only non-profit who can afford to lease office space in one of the most expensive locales in the country, midtown Manhattan on 5th Avenue. But it took me 11 months of pleading to everyone, the agency, DDD, the township, to get three disabled women an appropriate handrail installed so they could go in and out of their group home safely. Do not put anymore of our developmentally disabled citizens in jeopardy; they already have enough to deal with.



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Community Options Inc. > About Us > Mission

Mission

Community Options believes in the dignity of every person, and in the freedom of all people to experience the highest degree of self-determination. Embracing this philosophy, Community Options provides housing, support services and advocacy assistance to help empower people with disabilities.

Community Options, Inc. develops residential and employment supports for people with severe disabilities, utilizing technology and training. As a national agency, Community Options has participated in institutional closure and community residential placement for thousands of people across several states. Community Options does not administer any large congregate programs, recognizing that people with the most severe disabilities ~~need~~ environments, equipment, clinical and staff support that a tailored to their very specific needs. In its history, the agency has developed a reputation for quality, cost effective administration that encourages individual choice and flexibility.

Thank you for your support.

* operative word "recognize" not provide

RT @BinghamtonZoo: Thank you Community Options for providing our Amur tigers sisters with great enrichment items! http://t.co/1MxRm9y8Id

Enterprises Annual Report Cupid's Chase

Presents of Mind
Vanity
Daily Plan-It

Community Options
16 Farber Road, Princeton, New Jersey
P 609 951-9900|F 609 951
Our Offices | Cont

88x

DEPARTMENT OF HUMAN SERVICES
OFFICE OF LICENSING
LICENSURE INSPECTION REPORT
GROUP HOME Licensed Under N.J.A.C. 10:44A

REGION	**ACTIVITY DATE**
SRO	01/13/15
VID	**LICENSEE**
GH1992	Community Options, Inc.
SITE ADDRESS	**MAILING ADDRESS**
[redacted]	Same
MUNICIPALITY	**COUNTY**
Cherry Hill Township	Camden
TELEPHONE-RESIDENCE	**TELEPHONE-LICENSEE**
(856)216-2340	(609)265-7749
CENSUS	**CAPACITY**
Three (3)	Three (3)
EVALUATOR	**TITLE**
Paula Camarinha Renee Rivello-Nuss	Quality Assurance Specialist Quality Assurance Specialist
ACTIVITY	**LICENSE ACTION**
Reinspection After Negative Provisional	Full
FROM	**TO**
03/31/2015	09/30/2015
WAIVER/VARIANCE	**PLAN OF CORRECTION REQUIRED**
☐WAIVER ☐VARIANCE ☒NONE	☒Yes ☐No
DATA CORRECTION	**REASON FOR DATA CORRECTION**
None	N/A

[redacted] [redacted]

ADMINISTRATIVE INFORMATION

AGENCY REPRESENTATIVES

Name	Title
Colleen Hoffman	Executive Director
Erin Hansford	Community Support Coordinator
Letitia Carmichael	Community Support Manager

Code Reference Number	**Further Administrative Information**
6.1(b)	This residence is equipped with sprinklers, and is equipped with an independent inter-connected smoke alarm system that is linked to a central monitoring station. There are battery operated smoke detectors, separate from the inter-connected system, located in bedrooms #1 and #3. There are three battery operated carbon monoxide detectors located in the bedroom hallway, laundry room and basement.

Cite #	Code Ref. Number	Deficiencies
1.	2.2(a)	Documentation of the following critical information was not found in the critical information log: • was administered Ibuprofen PRN on 11/16/14, according to the MAR. The log did not indicate this administration occurred. • On 12/29/14 a medication change occurred with s Refresh eye drops. The medication was changed to 2 times a day (8am and 8pm). Documentation of the change was not found in the log. • On 1/6/15, s Refresh eye drops was changed from 2 times a day to 4 times a day (8am, 12pm, 4pm and 8pm). The medication change was not found in the log. • prednisolone acetate 1% eye drop 3 times a day was to be discontinued as of 12/5/14. *This information was not included in the* critical information log
2.	2.7(d)2	**Documentation that staff PH received training in s Behavior Support Plan (BSP) was not available. *PH was hired on 11/7/14, but she worked* alone on the 7am-3pm shift on 1/10/15.** **Failure to provide specialized training constitutes substantial non-compliance.**
3.		**Documentation that staff PH received training in the individuals low cholesterol diet was not available. PH was hired on 11/7/14, but she worked alone on the 7am-3pm shift on 1/10/15.** **Failure to provide specialized training constitutes substantial non-compliance.**

4. Documentation of staff training in the use of stroller was not available for any staff.

Failure to provide specialized training constitutes substantial non-compliance.

5. The Plan of Correction (POC) stated, "staff was retrained on agency Policy H-1: Program Record Keeping Procedures – Critical Information/Daily Log". However, documentation was not available that staff NK and KS received this training.

Failure to provide specialized training and one or more deficiencies specified in a POC as having been corrected by the licensee and have not, in fact, been corrected constitutes substantial non-compliance.

6. 4.3(a) Individual Habilitation Plan (IHP) modification to incorporate the Behavior Support Plan was not dated.

7. 5.1(e) A pattern was found of a failure to carry out physician's orders as evidenced by the following:

- On 11/21/14 Prednisilone Acetate 1% eye drops was prescribed 3 times a day (8am, 12pm, 8pm) for 2 weeks then discontinue and administer 2 times a day (8am and 8pm). The MAR indicated that the medication was administered 3 times a day for 16 days (starting on 11/21 and ending 12/7). The error was not circled in red or noted on the back of the MAR.
- On 11/23/14 two separate staff signed for the administration of Prednisilone Acetate 1% eye drops at 8am and 12pm on the MAR indicating that the medication was administered twice during those times rather than once as prescribed. The error was also not circled in red and not noted on the back of the MAR.
- On 12/10/14 , Debrox 6.5% ear drops was changed to 6pm Monday, Wednesday, Friday, AU. The December 2014 and January 2015 MARs indicated that Debrox 6.5% ear drops was to be administered in the left ear and the pharmacy label also indicated left ear. When asked what "AU" meant, the Agency Representative could not answer. At the time of the inspection, the Agency Representative contacted pharmacy for clarification and was informed that "AU" meant "both sides". Therefore, from 12/10/14 until the 1/12/15 staff was not administering the medication as prescribed.
- On 12/19/14 Prednisilone Acetate 1% was changed to 1 time a day (8am) for 14 days, which would have ended on 1/2/15. The MAR indicated that the medication was only administered from 12/20/14 – 12/30/14.
- On 12/29/14 Refresh eye drops was changed from 4 times a day to 2

times a day. The December and January MARs indicated that staff continued to administer 4 times a day on 12/29/14 through 1/6/15.

Failure to carry out physician's orders constitutes substantial non-compliance.

8. 5.2(b, c) The front of the January 2015 MAR for indicated that Ibuprofen was administered on 1/8/15. The back of the MAR indicated that the medication was administered on 1/8 and 1/9 for pain in her neck. The critical information log documented the 1/8 administration only. Therefore it is not known if the medication was administered on 1/9 as indicated on the front of the MAR.

9. The 12/13/14 medication administration boxes were not initialed as administered on the MAR for . .. The error was not circled in red or documented on the back of the MAR.

10. 5.2(b,c) **On 12/31/14 staff did not note the Pulse OX reading at 11:30pm and did not initial that the reading was taken. Documentation of the error was not circled in red and not noted on the back. The Agency could not verify that the treatment had been administered as prescribed.**

Failure to administer medication as prescribed constitutes sub-noncompliance.

11. On 11/21/14 staff documented pulse OX reading but did not sign his/her initials. Additionally, the MAR was blank for the 11:30pm reading for Pulse OX on 1/3/15, 1/4/15 and 1/9/15. Staff did not initial the MAR that the readings were taken but stated that was at a home visit on these dates.

12. 5.2(c)1vii The signature and corresponding initial for staff BO was not available on the back of October 2014 Medication Administration Record (MAR).

13. 5.2(e) January 2015 MAR indicated that Prednisilone Acetate 1% was administered 2 times a day (8am and 8pm) from 1/1/15 to 1/9/15. A corresponding physician's order was not available.

14. 6.2(a)1iii The information contained in the residence's Emergency Evacuation Plan (EEP) did not correspond to the information documented in . .. ; and Individual Emergency Evacuation Assessments (EEA). The EEAs state that both individuals require verbal and physical prompts to evacuate during the overnight fire drills which are not documented on the EEP.

15. 6.6(b) The same wooden railing present at the time of the 11/13/14 inspection located on the front step by the brick face exterior remains in place and found to be unsteady, and swayed back and forth.

A newly installed railing was put in place to remediate the previously cited deficiency. This second railing creates 2 potential safety hazards. The rough edged wood creates the potential for splinters and the new railing may require that an individual step down or lean over prior to being able to grasp the railing.

16. 6.6(c) The water temperature measured 122 degrees Fahrenheit.

DESCRIPTION OF BUILDING: N.J.A.C. 10:44A

GENERAL DESCRIPTION:

This is a ranch style residence. There are three means of egress which lead directly outside: th front door, sliding glass back door and laundry room door. There is an inoperable fireplace located i the living room. There is a natural gas heating system and central air conditioning and it is service by a public water supply and sewer system. The utilities are located in the basement.

FIRST FLOOR:

There is a kitchen, living room, dining room, laundry room, office, two and a half bathrooms and three bedrooms

SECOND FLOOR:

N/A

THIRD FLOOR:

N/A

ATTIC:

There is an access panel located in the hallway closet.

BASEMENT:

Partially finished with no means of egress, it will be used for storage only.

GARAGE AND OUTBUILDINGS:

There is an attached two-car garage that is used for storage.

APPROVED BEDROOM(S):

Bedroom #1: The bedroom is located down the hall the first door on the left. The room measures 10' x 13'9" for a total of 137 square feet. There is one window that measures 36" x 20" for a total of 5.1 square feet. There is a closet and furnishings include a bed, dresser, lamp, nightstand and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #2: The bedroom is located down the hall and straight ahead. The room measures 16'3" x 10' for a total of 162 square feet. There are two windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There is a closet and furnishings include a bed, dresser, nightstand, lamp and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #3: The bedroom is located down the hall on the right. The room measures 13'6" x 21' for a total of 283.5 square feet. There are four windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There are two closets and furnishings include a bed, dresser, nightstand, lamp, mirror and vanity with a sink. There is an attached bathroom which includes a toilet, sink and shower that is accessed through this room only. The bedroom is approved for occupancy by one individual.

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DEPARTMENT OF HUMAN SERVICES
OFFICE OF LICENSING
SPECIAL OPERATIONS
LICENSURE INSPECTION REPORT
Group Home Licensed Under. N.J.A.C. 10:44A

REGION SRO	**ACTIVITY DATE** 11/13/14
VID/LICENSE ID GH1992	**LICENSEE** Community Options, Inc.
SITE ADDRESS	**MAILING ADDRESS** Same
MUNICIPALITY	**COUNTY** Camden
TELEPHONE-RESIDENCE (856)216-2340	**TELEPHONE-LICENSEE** (609)265-7749
CENSUS Three (3)	**CAPACITY** Three (3)
EVALUATOR Renee Riviello-Nuss	**TITLE** Quality Assurance Specialist
ACTIVITY Unannounced Visit	**LICENSE ACTION** Provisional
LICENSE TERM - FROM 09/30/2014	**LICENSE TERM - TO** 03/31/2015
WAIVER/VARIANCE ☐WAIVER ☐VARIANCE ☒NONE	**PLAN OF CORRECTION REQUIRED** ☒Yes ☐No
DATA CORRECT None	**REASON FOR DATA CORRECTION** N/A
UIR #/ REPORTABLE EVENT # **COMPLAINT #**	

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ADMINISTRATIVE INFORMATION

AGENCY REPRESENTATIVES

Name	Title
Colleen Hoffman	Executive Director
Erin Hansford	Community Support Coordinator
Letitia Carmichael	Community Support Manager

SITE REVIEW NARRATIVE

An unannounced visit inspection (UV) was conducted by a representative from the Office of Licensing (OOL) at the above referenced program in response to a complaint that was received at the Office of the Commissioner to the Department of Human Services (DHS). It was reported that there is lack of support and services provided to an individual receiving services.

At the time of the visit the following was reviewed: RD's full record, staff training of RD's specialized needs, the emergency evacuation plan (EEP), and a review of the critical information log.

The following was found:

- Admission paperwork was not available in its entirety.
- Critical information and/or associated actions were not consistently documented in the critical information log.
- A review of s Medication Administration Records (MAR) revealed multiple times where staff failed to follow physicians' orders.
- A discrepancy with 's cash on hand was found as the actual balance to the in-house account funds did not match the balance from the financial ledger. There was a difference of $7.33 in 's favor.
- The emergency evacuation plan (EEP) was available and included the evacuation needs of all the individuals and the supports to be provided by staff.
- A review of staff training revealed multiple staff not trained in s behavior support plan (BSP).

Deficiencies found at the time of the visit are noted below.

ITEM #	LICENSURE STANDARD	STATEMENT OF DEFICIENCES
1	2.2(a)	Critical information and corresponding associated actions are not consistently documented in the critical information log. For example, on 9/15/14 had a follow-up medical appointment with her oncologist. The medical consult form indicated that she was being treated as she has a history of breast cancer and osteopenia. A follow-up appointment was scheduled for 12/15/14. The corresponding critical information log indicated her medical appointment on 9/15/14 and not the date of the follow-up appointment.
2		The critical information log did not consistently document medication errors

		for [redacted] Below are examples: • 8/21/14 – Metformin was administered when the medication was to be held due to surgery. • 8/21/14 – [redacted] the MAR noted "H" for the administration of the multivitamin. The symbol "H" indicates a home visit; however, [redacted] was at the hospital on 8/21/14. • 9/20/14 to 9/22/14 - Omnipred (prednisolone-acetate was administered prior to surgery instead of after surgery.
3		Staff inconsistently documented the administration of [redacted]s PRN oxycodone-acetaminophen 5-325mg tablets in the critical information log. For example: The August 2014 MAR indicated that [redacted] was administered the medication on 8/21/14 at 4pm and 8pm.
4	2.2(a) 2.10(e)	The authorization of entrustment form, dated and signed 7/14/14, indicates that only payments received from [redacted] family is entrusted to the Agency. Additionally, the Agency is authorized to maintain up to $200.00 of RD's money in the in-house account. [redacted]s financial ledgers indicate that the Agency representative made withdrawals and deposits to [redacted]s bank account in accordance with [redacted]s guardian's approval. Documentation was not available that the entrustment of funds form was updated to include funds from other sources.
5	**2.7(d)2**	**Documentation was not available that the following staff received training in [redacted]s BSP: [redacted]** **Failure to assure staff receive training in specialized training programs constitutes substantial non-compliance.**
6		The EEP training roster does not identify the EEP for which the staff are being trained. Rather, it is a continuous running list of dated signatures of staff.
7	2.9(d)1viii	Documentation was not available of [redacted]s pre-admission information such as developmental history and/or a psychological evaluation.
8	2.10(d)	Documentation was not available that [redacted] and/or her guardian received the Agency's policy and procedure for safekeeping and management of funds.
9	2.10(e)	A discrepancy was found with the money available in [redacted]s in-house account and the financial ledger. According to the financial ledger RD was to have $68.34 available. However, the available money totaled $75.67. This was a difference of $7.33 in [redacted]s favor.
10	3.1(b)1	*Documentation was not available that [redacted]and/or her guardian received a* copy of the Division of Developmental Disabilities (DDD) Individual Rights document.

11	3.1(b)2	Documentation was not available that [redacted] and/or her guardian received the list of Advocates.
12	3.1(b)4	Documentation was not available that [redacted] and/or her guardian received the Agency's grievance procedure.
13	3.2(a)2 4.1(e)3	Documentation was not available that [redacted] and/or her guardian received the Agency's governing rules.
14	4.1(e)1	Documentation was not available that [redacted] and/or her guardian received the *Agency's procedure for safekeeping of valuable personal possessions.*
15	4.1(e)5	Documentation was not available that [redacted] and/or her guardian received the Agency's policy related to toll calls and/or charges.
16	4.3(a)	[redacted] Individual Habilitation Plan (IHP) modification, dated 8/26/14, does not indicate that a BSP is in place. The BSP is dated 7/6/14. Additionally, [redacted] guardian consent to the implementation of the BSP was not available.
17	5.1(e)	**The following instances of staff not adhering to physicians' orders for [redacted] were found:** • **Physician orders, dated 9/12/14, for [redacted] indicated that after surgery (9/23/14) Omnipred (prednisolone-acetate) was to be administered to the left eye. However, the September 2014 MAR revealed, the Omnipred (prednisolone-acetate) was *administered prior to surgery on 9/20, 9/21 and 9/22.*** • **Discontinue orders, dated 9/23/14, indicate that Refresh tear drops and Refresh ointment medications were being discontinued for the left eye. The medication was to continue for the right eye. The September 2014 MAR indicates that the medications were discontinued for both eyes as of 9/23/14. The October 2014 and November 2014 MARs indicate that the medications were administered to both eyes.** **Failure to carry out physicians' orders constitutes substantial non-compliance.**
18	5.1(e)1	**[redacted] was taken to the hospital emergency room on 11/1/14. The hospital discharge paperwork indicated follow-up as, "follow-up with primary care physician as needed, follow-up with specialist as instructed". The specialist identified on the discharge paperwork was "Behavioral Health, Kennedy, Psychiatry". Documentation was not *available that contact was made with this specialist.*** **Failure to provide medical follow up constitutes substantial non-**

		compliance.
19	5.2(b) 5.2(c)	There were several instances of medication errors for in which, documentation was not available indicating whether or not the prescribing physician(s) were notified and the error was not documented on the MAR. Below are examples: • 8/21/14 – Metformin was administered when the medication was to be held due to surgery. • 8/21/14 – the MAR noted "H" for the administration of the multivitamin. The symbol "H" indicates a home visit; however, was at the hospital on 8/21/14. • 9/20/14 to 9/22/14 - Omnipred (prednisolone-acetate was administered prior to surgery instead of after surgery. • 10/30/14 – Critical information log indicated refused 4 + 5 pm medications and subsequently received.
20		The August 2014 MAR indicated that was administered her PRN oxycodone-acetaminophen 5-325mg on 8/21/14 at 4pm and 8pm; however, the explanation of the administration was not documented on the back of the MAR. The 8/23/14 critical information log indicated that was administered PRN oxycodone-acetaminophen 5-325mg at 8am and 8pm. However, the corresponding MAR noted the medication was administered at 8am. The back of the MAR indicated that the medication was administered at 8am and 5pm.
21		is to be administered Refresh eye drops at 4pm, Alprazolam 0.5mg at 4pm, Levothyroxine 88mcg at 4pm, and Metformin HCL 500mg at 5pm. An entry in the critical information log, dated 10/30/14, indicated that "…*refused to take her 4 + 5pm meds, from staff, later on she came out,* because she said she was hungry. Then she took her meds, and ate a little at her dinner…" The corresponding MAR did not indicate a medication refusal for the medications administered nor did it indicate the time of administration.
22	5.3(b)	The 8/14/14 critical information log indicated that Kaopectate, over the counter (OTC) medication, was administered to at 11:15pm. Documentation of this administration was not found on the corresponding MAR.
23	6.2(b)1	s Emergency Evacuation Assessment (EEA) was not available.
24	6.6(b)	The wooden railing on the front steps was very unsteady and swayed back and forth when used.
25	6.6(c)	The sink in the hallway partial bathroom contained a leaky faucet.

DESCRIPTION OF BUILDING: N.J.A.C. 10:44A

GENERAL DESCRIPTION:

This is a ranch style residence. There are three means of egress which lead directly outside: the front door, sliding glass back door and laundry room door. There is an inoperable fireplace located in the living room. There is a natural gas heating system and central air conditioning and it is serviced by a public water supply and sewer system. The utilities are located in the basement.

FIRST FLOOR:

There is a kitchen, living room, dining room, laundry room, office, two and a half bathrooms and three bedrooms

SECOND FLOOR:

N/A

THIRD FLOOR:

N/A

ATTIC:

There is an access panel located in the hallway closet.

BASEMENT:

Partially finished with no means of egress, it will be used for storage only.

GARAGE AND OUTBUILDINGS:

There is an attached two-car garage that is used for storage.

APPROVED BEDROOM(S):

Bedroom #1: The bedroom is located down the hall the first door on the left. The room measures 10' x 13'9" for a total of 137 square feet. There is one window that measures 36" x 20" for a total of 5.1 square feet. There is a closet and furnishings include a bed, dresser, lamp, nightstand and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #2: The bedroom is located down the hall and straight ahead. The room measures 16'3" x 10' for a total of 162 square feet. There are two windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There is a closet and furnishings include a bed, dresser, nightstand, lamp and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #3: The bedroom is located down the hall on the right. The room measures 13'6" x 21' for a total of 283.5 square feet. There are four windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There are two closets and furnishings include a bed, dresser, nightstand, lamp, mirror and vanity with a sink. There is an attached bathroom which includes a toilet, sink and shower that is accessed through this room only. The bedroom is approved for occupancy by one individual.

100x

DEPARTMENT OF HUMAN SERVICES
OFFICE OF LICENSING
LICENSURE INSPECTION REPORT
GROUP HOME Licensed Under N.J.A.C. 10:44A

REGION	**ACTIVITY DATE**
SRO	10/6/2014
VID	**LICENSEE**
GH1992	Community Options, Inc.
SITE ADDRESS	**MAILING ADDRESS**
[redacted]	Same
MUNICIPALITY	**COUNTY**
Cherry Hill Township	Camden
TELEPHONE-RESIDENCE	**TELEPHONE-LICENSEE**
(856)216-2340	(609)265-7749
CENSUS	**CAPACITY**
Three (3)	Three (3)
EVALUATOR	**TITLE**
Lucrezia Krolikowski	Quality Assurance Specialist
ACTIVITY	**LICENSE ACTION**
Routine Reinspection	Provisional
FROM	**TO**
09/30/2014	03/31/2015
WAIVER/VARIANCE	**PLAN OF CORRECTION REQUIRED**
☐WAIVER ☐VARIANCE ☒NONE	☒Yes ☐No
DATA CORRECTION	**REASON FOR DATA CORRECTION**
None	N/A

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ADMINISTRATIVE INFORMATION

AGENCY REPRESENTATIVES

Name	Title
Mattie Loban	Executive Director
Kelle Callender	Community Support Coordinator
Bosede Olagbaju	Registered Nurse
Letitia Carmichael	Community Support Manager

Code Reference Number	Further Administrative Information
6.1(b)	This residence is equipped with sprinklers, and is equipped with an independent inter-connected smoke alarm system that is linked to a central monitoring station. There are battery operated smoke detectors, separate from the inter-connected system, located in bedrooms #1 and #3. There are three battery operated carbon monoxide detectors located in the bedroom hallway, laundry room and basement.

Cite #	Code Ref. Number	Deficiencies
1.	2.2(a)	Critical information was not consistently documented in the agency's critical logs, for example, the following was not available: • On 9/30/14, the physician wrote an order to have s fluid intake monitored and tracked as she is not drinking an adequate amount of fluids and, • on 8/24/14 all of 's 10:00AM medications were not given due to a severe seizure as mother stated not to give her medication and this information was not included in the log.
2.	2.2(a) 2.2(b)5	**Staff reported had a seizure on 9/23/14 and 911 was not called, per mother's request that she is to be called first. When questioned, staff reported at the time of inspection that the mother lives close by and *insists that she be called first. Mother took her daughter to the* Emergency room. The Executive Director stated that practice must stop immediately and that all staff will be retrained as 911 must be called first.** **In addition, there was no documentation available that the failure to call 911 was reported to the Department of Human Services.** **Failure to immediately call 911 in compliance with Danielle's Law in the event of a life-threatening emergency and failure to report all unusual incidents constitutes substantial non-compliance.**
3.	2.3(b) 6.3(a)2	**Staff present at the inspection was initially unable to operate the fire alarm system when instructed to test the system. The drill was completed with much difficulty as it took several minutes with four staff to figure out how**

to turn the system on and off.

The lack of knowledge of emergency procedures by staff constitutes substantial *non-compliance.*

4. 2.6(a)4 **The following staff worked in the home prior to being trained in the Emergency Evacuation Plan (EEP): BB, EH, DY & RB.**

Failure to ensure all staff is trained in the EEP constitutes substantial noncompliance.

5. 2.7(d)2 **Documentation was not available that any staff received training in what constitutes s fluid intake program.**

Failure to assure all staff receives specialized training constitutes substantial noncompliance.

6. 2.8(d) The staff schedule did not consistently identify the times of the shift of the employees. For example, the day shift *11:00 AM – 7:00 PM is written as 11-7* and so is the overnight shift of 11PM-7AM.

7. The staff schedule did not consistently identify the employee in charge on each *shift. For example, on 9/20/14 & 9/21/14*, two staff were assigned to work each shift; however, the employee in –charge was not identified.

8. The staff scheduled indicated that BB worked in the home on 9/20/14, However, when questioned staff stated that BH actually worked that shift.

Additionally, the staff schedule for the week of 9/27/14 to 10/3/14 did not include the name or initials of EH who staff reported worked all week.

9. 3.1(b)2v s list of advocates did not identify her case manager.

10. 3.2(d) House meeting minutes were not available for 8/2014 & 9/2014.

11. 5.1(e) **A review of s Medication Administration Record (MAR) revealed the following issue: On 8/24/14, all 10:00AM medications were not given. The boxes were not circled *in red and were not initialed by staff. The* explanation on the back of the MARS stated that medication was not given due to a severe seizure as mother was called and stated not to give her medication.**

Failure to carry out physician orders constitutes substantial noncompliance.

12. **There was documentation on s inventory sheet of her adaptive equipment, a stroller and a shower chair. When questioned regarding the long list of items on the sheet, staff present stated that no longer has a stroller as her mother took it back, and that does not have a shower chair. When this inspector questioned further due to s diagnosis of seizures and her prescription for a shower chair, staff located the shower chair in 's bedroom. The staff was unaware that needs to bathe**

using a shower chair.

Failures to follow a physician's order constitute substantial non-compliance and provide treatment for individuals with known special needs.

13. 5.2(c) The codes on 's preprinted Medication Administration Record (MAR) for August, September and October 2014 were not the codes approved in the NJ Pre-Service staff training.

14. 5.5(a) A pantry closet near the laundry room had three packages of water stored on the floor.

15. 5.5(d)1 The weekly menus were exactly the same with no variety or rotation and staff stated that the individuals had no input into the menus.

16. 5.5(f)2 **& each have a physician's order for a medically prescribed diet. is on a 1400 calorie gluten free diet that is to be cut into small pieces and has to have her fluid intake monitored and tracked. is on an 1800 calorie ADA diet. Documentation of these orders was not on the menus.**

Failure to implement medically prescribed diets constitutes substantial non-compliance.

17. 6.1(b) The current fire inspection certificate was expired as it was dated 7/18/14.

18 6.2(a)1 s individual Emergency Evacuation Assessment (EEA) checks off all three boxes under the Mobility section that she walks independently, walks with aids and occasionally needs help. There is no explanation provided where it states to explain. When questioned, staff present stated that has seizures; she can ambulate independently but during an evacuation staff provides her with physical assistance by taking her under her arm and right after a seizure she is disoriented and unable to take verbal direction. If she is having a seizure during a true emergency, she will actually need physical assistance; and if it occurs right after a seizure she is disoriented. Additionally, The EEP states that is ambulatory with verbal prompts with no information regarding her needs if she is having or after having a seizure.

19 was admitted to the home on 4/10/14 however, the EEA was not signed by the author or dated.

20 6.2(b) The Emergency Evacuation Plan (EEP) was revised to include the recent admission on 7/28/14 but the EEP was not dated.

21 s EEA was dated 7/26/13. There was no documentation available for a current annual review date.

22 6.2(b)1 was admitted to the home on 7/28/14 however, an individual Emergency Evacuation Assessment (EEA) was not completed.

23 6.6(b) The exterior dryer vent flap was open and would not properly close.

24		A drain spout was disconnected in the side of the house and was laying in the yard.
25	6.6(c)	The Carbon Monoxide detector (CO) located in the basement was malfunctioning as it did not properly beep when sounded.
26		The battery operated smoke detector located in s bedroom did not beep when sounded.

DESCRIPTION OF BUILDING: N.J.A.C. 10:44A

GENERAL DESCRIPTION:

This is a ranch style residence. There are three means of egress which lead directly outside: the front door, sliding glass back door and laundry room door. There is an inoperable fireplace located in the living room. There is a natural gas heating system and central air conditioning and it is serviced by a public water supply and sewer system. The utilities are located in the basement.

FIRST FLOOR:

There is a kitchen, living room, dining room, laundry room, office, two and a half bathrooms and three bedrooms

SECOND FLOOR:

N/A

THIRD FLOOR:

N/A

ATTIC:

There is an access panel located in the hallway closet.

BASEMENT:

Partially finished with no means of egress, it will be used for storage only.

GARAGE AND OUTBUILDINGS:

There is an attached two-car garage that is used for storage.

APPROVED BEDROOM(S):

Bedroom #1: The bedroom is located down the hall the first door on the left. The room measures 10' x 13'9" for a total of 137 square feet. There is one window that measures 36" x 20" for a total of 5.1 square feet. There is a closet and furnishings include a bed, dresser, lamp, nightstand and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #2: The bedroom is located down the hall and straight ahead. The room measures 16'3" x 10' for a total of 162 square feet. There are two windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There is a closet and furnishings include a bed, dresser, nightstand, lamp and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #3: The bedroom is located down the hall on the right. The room measures 13'6" x 21' for a total of 283.5 square feet. There are four windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There are two closets and furnishings include a bed, dresser, nightstand, lamp, mirror and vanity with a sink. There is an attached bathroom which includes a toilet, sink and shower that is accessed through this room only. The bedroom is approved for occupancy by one individual.

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DEPARTMENT OF HUMAN SERVICES
OFFICE OF LICENSING
LICENSURE INSPECTION REPORT
GROUP HOME Licensed Under N.J.A.C. 10:44A

REGION	**ACTIVITY DATE**
SRO	10/08/2013
VID	**LICENSEE**
GH1992	Community Options, Inc.
SITE ADDRESS	**MAILING ADDRESS**
[redacted]	Same
MUNICIPALITY	**COUNTY**
Cherry Hill Township	Camden
TELEPHONE-RESIDENCE	**TELEPHONE-LICENSEE**
[redacted]	(973)872-7111
CENSUS	**CAPACITY**
Three (3)	Three (3)
EVALUATOR	**TITLE**
Renee Riviello-Nuss	Quality Assurance Specialist
ACTIVITY	**LICENSE ACTION**
Routine Reinspection	Full
FROM	**TO**
09/30/2013	09/30/2014
WAIVER/VARIANCE	**PLAN OF CORRECTION REQUIRED**
☐WAIVER ☐VARIANCE ☒NONE	☒Yes ☐No
DATA CORRECTION	**REASON FOR DATA CORRECTION**
None	N/A

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ADMINISTRATIVE INFORMATION

AGENCY REPRESENTATIVES

Name	Title
Zlin McCoy	Assistant Executive Director
Kelle Callender	Community Support Coordinator
Jennifer Oates	Community Support Coordinator

Code Reference Number	Further Administrative Information
2.7(c)3 2.7(d)2	Documentation was not available that the following staff received training in the administration of Diazepam injectable medication by a Registered Nurse (RN): LH, RabB, AT, JJ, RasB, LC, TR, EB, CS, JH, AS, PB, and BP. The Agency is advised injectable medications must be trained by at least an RN.
6.1(a)	Although the home was registered with Department of Community Affairs (DCA) on 6/10/13, The DCA Life Hazard Use certificate was not available.
6.1(b)	This residence is equipped with sprinklers, and is equipped with an independent inter-connected smoke alarm system that is linked to a central monitoring station. There are battery operated smoke detectors, separate from the inter-connected system, located in bedrooms #1 and #3. There are three battery operated carbon monoxide detectors located in the bedroom hallway, laundry room and basement.

Cit. #	Code Ref. Number	Deficiencies
1	2.2(a)	The acknowledgment form for [redacted] was signed by her guardian on 7/26/13; however, the form was not checked that the following information was provided: safe keeping and management of funds policy, Division of Developmental Disabilities Rights document, list of Advocates, Grievance procedure, Governing rules, safekeeping of valuable personal possessions policy and toll charges policy.
2	2.2(a)	Critical information was not consistently documented in the critical information log. For example, on 9/8/13, [redacted] received a physician's order for [redacted] 1 daily for 14 days, upon her discharge from Virtua Hospital Emergency Room (ER). Documentation of the ER visit was noted in the log; however, the medication change was not.
3	2.2(a)	[redacted] August 2013 Medication Administration Record (MAR) indicated that [redacted] cream was discontinued on 8/14/13. The critical information log did not indicate that the medication was discontinued.
4	**2.6(a)4**	**Documentation was not available that the following staff received training in the specialized training program for the 8/9/13 Emergency Evacvuation Plan (EEP): CS (date of hire 8/23/13), EB (date of hire 8/20/13), and TR (date**

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		of hire 7/23/13). Failure to assure staff receive training in specizlied training programs constitutes substantial non-compliance.
5	2.6(a)5	Documentation was not available that all staff received training in the specialized training program for what constitutes a pureed diet. Failure to assure staff receive training in specialized training programs constitutes substantial non-compliance.
6	2.6(a)5	Documentation was not available that the following staff received training in the specialized training program involving the administration of a Nebulizer: CS (date of hire 8/23/13), EB (date of hire 8/20/13), LH (date of hire 7/30/13), and AS (date of hire 7/26/13). Failure to assure staff receive training in specialized training programs constitutes substantial non-compliance.
7	2.6(a)5	Documentation was not available that the following staff received training in the specialized training program for the use of adaptive equipment: CS (date of hire 8/23/13), EB (date of hire 8/20/13), LH (date of hire 7/30/13), AS (date of hire 7/26/13), BP (date of hire 10/3/13), RabB (date of hire 9/7/11), JH (date of hire 8/27/13), AT (date of hire 5/14/12), JJ (date of hire 7/30/13), PB, (date of hire 9/16/13), SH (date of hire 9/19/02), JO (date of hire 5/8/13), TR (date of hire 7/23/13), RasB (date of hire 3/8/13), and LC (date of hire7/10/13). Failure to assure staff receive training in specialized training programs constitutes substantial non-compliance.
8	2.6(a)5	Documentation was not available that the following staff received training in the specialized training program for Anemia: CS (date of hire 8/23/13), EB (date of hire 8/20/13), LH (date of hire 7/30/13), AS (date of hire 7/26/13), BP (date of hire 10/3/13), RabB (date of hire 9/7/11), JH (date of hire 8/27/13), TR (date of hire 7/23/13), RasB (date of hire 3/8/13), and LC (date of hire7/10/13). Failure to assure staff receive training in specialized training programs constitutes substantial non-compliance.
9	2.6(a)5	Documentation was not available that the following staff received training in the specialized training program heart murmer: CS (date of hire 8/23/13), EB (date of hire 8/20/13), LH (date of hire 7/30/13), AS (date of hire 7/26/13), BP (date of hire 10/3/13), RabB (date of hire 9/7/11), JH (date of hire 8/27/13), TR (date of hire 7/23/13), RasB (date of hire 3/8/13), and LC (date of hire7/10/13) and PB (date of hire (9/16/13). Failure to assure staff receive training in specialized training programs constitutes substantial non-compliance.

10	**2.6(a)5**	**Documentation was not available that the following staff received training in the specialized training program for administering nectar thickened liquids: CS (date of hire 8/23/13), EB (date of hire 8/20/13), LH (date of hire 7/30/13), and AS (date of hire 7/26/13).** **Failure to assure staff receive training in specizlied training programs constitutes substantial non-compliance.**
11	2.7(d)2	Documentation was not available of the dated signature of the trainer for the trainings corresponding to the 8/9/13 EEP, Anemia and Heart Murmer.
12	2.8(d)	The staff schedule did not consistently identify the employee in-charge on each shift. For example, on 10/6/13, two (2) staff were assigned to work the 7am – 3pm shift; however, the employee in-charge was not identified.
13	2.10(f)2	[redacted] August 2013 ending financial ledger balance was $145.55. Documentation was not available to indicate that maintaining a balance over $100.00 was authorized.
14	3.1(b)2iii	[redacted] list of advocates contained an inaccurate contact information for the Office of Licensing.
15	3.1(b)2v	[redacted] list of advocates did not identify her case manager.
16	4.3(c)10	[redacted] Essential Life Plan (dated 10/27/12, 3/1/13, 8/23/13) did not include whether barriers to the plan exist.
17	5.1(e)	[redacted] record contained an undated and unsigned note on the letterhead of [redacted] APN, which stated, "Please discontinue [redacted] medications in liquid form and provide her medications as tablets." Additionally, [redacted] August 2013 MAR reflected that her liquid medications were discontinued as of 8/14/13 and the corresponding oral medication were started as ordered; however, documentation was not available to verify the medications were to be discontinued as of 8/14/13.
18	**5.1(e)**	**The undated and unsigned note on the letterhead of [redacted]s APN also included that [redacted] is to be discontinued. However, [redacted] August 2013 MAR indicated that the medication was administered the entire month. The September 2013 MAR indicated that the medication was discontinued as of 9/11/13.** **Failure to follow physician's orders constitutes substantial noncompliance.**
19	5.2(b)	The October 2013 MAR was blank for 10/1/13 – 10/3/13 for the administration of [redacted] at 8am and 8pm.
20	5.2(c)1vii	The first and second page of the [redacted] July 2013 MAR did not include the initials and corresponding signatures of staff administering medication.
21	5.2(c)1vii	The August 2013 MAR that included the physician's order for brushing [redacted] teeth two (2) times daily did not include the cooresponding signatures of staff SH, JJ and AS who implemented this order.

22	5.2(g)1	[redacted] August 2013 Medication Administration Record (MAR) indicated that [redacted] was discontinued on 8/14/13. However, documentation of the physician's order to discontinue this medication was not available.
23	5.2(h)	Acetaminophen 500 mg tablets were not available with [redacted] over-the-counter medications.
24	5.5(f)2	The current menu identified [redacted] diet as double portions, thin liquids, regular. However, a 9/30/13 physician's order indicated the diet as double portions.
25	6.1(b)	A current inspection certificate from the fire official was not available.
26	6.6(c)	The carbon monoxide detector in the bedroom hallway did not reset after being tested.

///x

DESCRIPTION OF BUILDING: N.J.A.C. 10:44A

GENERAL DESCRIPTION:

This is a ranch style residence. There are three means of egress which lead directly outside, the front door, sliding glass back door and laundry room door. There is a gas heating system and central air conditioning and it is serviced by a public water supply and sewage system. The utilities are located in the basement.

FIRST FLOOR:

There is a kitchen, living room, dining room, office, two and a half bathrooms and three bedrooms.

SECOND FLOOR:

N/A

THIRD FLOOR:

N/A

ATTIC:

Yes, not used for storage.

BASEMENT:

Yes, with only means of egress.

GARAGE AND OUTBUILDINGS:

Two car attached garage.

APPROVED BEDROOM(S):

Bedroom #1: The bedroom is located down the hall the first door on the left. The room measures 10' x 13'9" for a total of 137 square feet. There is one window that measures 36" x 20" for a total of 5.1 square feet. There is a closet and furnishings include a bed, dresser, lamp, nightstand and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #2: The bedroom is located down the hall and straight ahead. The room measures 16'3" x 10' for a total of 162 square feet. There are two windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There is a closet and furnishings include a bed, dresser, nightstand, lamp and mirror. The bedroom is approved for occupancy by one individual.

Bedroom #3: The bedroom is located down the hall on the right. The room measures 13'6" x 21' for a total of 283.5 square feet. There are four windows each measuring 38" x 18" from sill to head and jamb to jamb, for a total of 12.6 square feet. There are two closets and furnishings include a bed, dresser, nightstand, lamp and mirror. The bedroom is approved for occupancy by one individual.

Jesse Meril

Chronologically, 21 years old, mentally & emotionally he will always be a vulnerable 8 year old who trusts everyone, he has no understanding of stranger danger. At his current placement, Triform Camphill Community in New York State, he is a happy, productive & safe member of his community.

My son Jesse is classified multiply disabled and has been a resident at a Camphill Community for 10 years. This model works because it is a safe campus built around a farming community and it is an electronic free environment with no TV's or readily available computers in the homes. Before we found Camphill, Jesse was highly medicated for severe behavior issues. Since we found Camphill Communities, he is medication free, living and working in a safe, rural farming community. He is happy, productive & most important, safe!

Triform Camphill Community is the most cost effective placement for Jesse & saves New Jersey tens of thousands of dollars.

Leslie A. Meril, Co---Guardian & Mom --- LatMeril@gmail.com

Samantha N. Meril, Co---Guardian & Twin Sister

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Comments

Re: Jesse Meril – long term support for **lower cost** out of state placement.

Good afternoon and thank you for this opportunity to appear before your committee today. This is the first time I have ever done anything like this.

Hello, I am Leslie Meril, a single mother of a multiply disabled young adult; I had to take the day off from work to be here with you today. I want all of you to know that I am extremely grateful for this opportunity, it is so important to our family.

My purpose for being here today is to advocate on behalf of my son Jesse, DDD has denied funding for his current placement for being out of state, but not because it doesn't meet his needs, or that there is a comparable existing facility in NJ. Jesse is a 21 year old disabled young adult with the mental capacity of an 8 year old and he will age out of our local school district in Allendale, NJ at the end of this month on June 30, in 20 days…

For 10 years he has been in a safe & cost effective rural residential program out of New Jersey called Camphill.

In New Jersey his current annual DDD budget is $142,400.00

The very low annual cost to maintain his current program at Triform Camphill, in Hudson, NY is only $60,765.00, this is much less than the budget allocated for Jesse.

I am asking DDD to continue funding for Jesse's current program because it is the only placement that meets his special needs. He has very difficult to manage behaviors due to a traumatic brain injury at birth.

No behavior modification methods worked for Jesse, prior to Camphill he attended multiple local New Jersey public & private schools, without success for he or his teachers.

When behavior modification methods proved ineffective Jesse was highly medicated; medication also proved to be grossly ineffective.

Triform Camphill in Hudson, NY model works for Jesse because it is:

- A campus built around a farming community where Jesse works and lives with a family & support staff in a house on the campus.
- Electronic free environment
- NO TV's,
- No readily available computers
- No electronic games.
- Weekdays he goes to work every morning and class every afternoon
- Structured activities on weekends with opportunity to participate in culturally rich drama, music, art classes & more
- He has 24/7 support & supervision by a network of caring staff who are like extended family, they live and work alongside the residents.

You might ask me, what has DDD, New Jersey offered as an alternative? The answer, a much more expensive ONE SIZE FITS ALL that does NOT meet Jesse's needs! A group home in a main stream neighborhood, with 3 much older residents and a stranger hired to watch them, with no plan for a structured work or study day programs. When I asked about the day program, I was told; after we meet him we will figure it out. They couldn't even provide an example.

Jesse cannot work at a grocery store or local business, main stream is over stimulating to him, he will act out and he will be put in harm's way with DDD's more expensive ONE SIZE FITS ALL plan.

I have received more than eight (8) referrals from DDD, none of them could provide Jesse with the level of care he currently receives, or on a more cost effective basis – safe, farm, campus, electronic free environment where he can walk to work and attend educational classes learning life skills, such as: Farming, Gardening, Bakery, Home Economics, The Weavery, and Pottery with a structured afternoon education program.

I ASK YOU, WHO'S BENEFITING FROM RETURN HOME NEW JERSEY?

I found a cost effective & safe home for Jesse 10 years ago.

Trform Camphill saves New Jersey and our Federal Government tax money in comparison to the expensive DDD alternatives offered.

On the NEW JERSEY, Department of Human Services, DDD web page it states that the goal of Return Home NJ is twofold and I quote: "to ensure that individuals who have been placed out of state can return to a comparable or better setting in New Jersey that meets their needs and to better manage the state resources . . ."

With this in mind, how does returning Jesse home to NJ achieve these goals?

AGAIN, I ASK . . .

WHO'S BENEFITING FROM RETURN HOME NEW JERSEY?

CERTAINLY NOT Jesse and NOT the NJ TAX PAYERS EITHER . . .

Please help me protect my son Jesse and save NJ money, I am asking for less money to continue in a safer, more supportive placement; common sense should prevail.

Thank you again for affording me this opportunity, I am very grateful.

$142,400

STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES
PO BOX 726
TRENTON, NJ 08625-0726
609.631.2200
www.nj.gov/humanservices/ddd

CHRIS CHRISTIE
GOVERNOR

KIM GUADAGNO
LT. GOVERNOR

Elizabeth Connolly
Acting Commissioner

Dawn Apgar
Deputy Commissioner

Elizabeth M. Shea
Assistant Commissioner

May 28, 2015

Re: Jesse Meril

Dear Ms. Meril,

You have requested information regarding Jesse's current New Jersey Comprehensive Assessment Tool (NJCAT) scores and the corresponding budget associated with his scores. The assessment completed on 1/15/2015 yielded scores of 3-3-1. The current corresponding "up to budget" for this scoring is $142,400 to cover residential and day services costs annually.

The DDRT assesses an individual's vulnerabilities in the areas of self-care, behavioral and medical, and determines relative need for services and supports. This information is used to ensure that individuals with like needs receive a similar level of support. If Jesse's needs change in such a way that he requires more or less support, a new assessment can be requested.

I can be reached at 973-927-2611 if you should have any additional questions.

Sincerely,

Tina R. McDuffie
DDD Intensive Case Management Unit Director

Why ?

STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
DIVISION OF DEVELOPMENTAL DISABILITIES

- DHS Home
- Division of Developmental Disabilities Home
- Services and Supports
- **Major Programs and Initiatives**
  - Self-Directed Services
  - Olmstead
  - Crisis Response System (CRS)
  - Commissioner's Task Force on Dual Diagnosis
- Important Resources
- News, Publications and Reports
- Information for Providers & Stakeholders: Contracts, Legal Notices
- Division Staff & Contact Information
- Public Advisory Boards, Commissions & Councils
- Important Alerts

DHS Home > Division of Developmental Disabilities > Major Programs and Initiatives > Return Home New Jersey

Return Home New Jersey

Related Links

RHNJ Testimony: June 12, 2014

New Jersey's Return Home policy brings back to New Jersey adults with intellectual and developmental disabilities – many of whom were placed out of state as students with special needs and who transitioned into costly, congregate residential facilities upon graduation. At the time, there was no 'trigger' to return them to New Jersey when their educational entitlement ended, so they have been living in another state, in an institutional setting, paid for with New Jersey tax dollars for years, even decades.

Over the past several years, New Jersey's system of care for people with intellectual and developmental disabilities has steadily evolved. Hundreds of millions of dollars have been invested into community-based homes and services to give people with intellectual and developmental disabilities opportunities to live, work and enjoy their lives in smaller residential settings, with appropriate staff and services to support them. This absolutely includes people with very complex medical needs and behavioral conditions.

It makes sense that with a growing infrastructure in place to serve them, we should return this group of people – closer to family, into community-based residential settings that are licensed and inspected according to New Jersey standards.

The goal of Return Home New Jersey is twofold: to ensure that individuals who have been placed out of state can return to a comparable or better setting in New Jersey that meets their needs and to better manage the state resources that serve the community of nearly 29,000 people with intellectual and developmental disabilities in New Jersey – which includes the waiting list and others who are transitioning from developmental centers into the community.

The facts are:

- Since 2010, New Jersey has successfully transitioned over 100 people from out-of-state back to New Jersey.
- For decades, families and professionals have recognized the value of caring for people with developmental disabilities in community settings. Care systems are being transformed across this nation in recognition of the benefit of living a community life.
- About 280 state-contracted provider agencies in New Jersey meet the wide variety of needs of adults with developmental disabilities, even the most medically complex.
- Residential programs in New Jersey often provide a higher level of supervision than institutions, with 4 individuals and two staff during daytime hours, while most out-of-state agencies offer a ratio of one staff to 4-6 residents.
- New Jersey residential programs include day services and activities for residents to attend. Additionally, there is a comprehensive system of care that surrounds an individual and his or her needs when, for example, a psychiatric or other crisis emerges.
- New Jersey's residential programs are monitored and must meet rigorous licensing standards. The programs are inspected annually, with

unannounced visits if concerns are raised. Any serious incidents are investigated by the provider, DHS and if appropriate, local or state police.

- The New Jersey Central Registry of Offenders also protects from the potential rehiring of any offender in the service system.
- Most existing out-of-state placements are not Medicaid reimbursable, which means they are paid with state-only funds. At least half of the annual cost of in-state community programs is paid by federal matching funds, which frees up state dollars to provide services to others who are eligible.
- There are individuals who were years ago placed out of state, whose family has long left New Jersey – and New Jersey, to date, has continued to pay for this out of state care.

OPRA | Open Public Records Act

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$60,765

TRIFORM
Camphill Community

May 27, 2015

Dear Parents and Guardians,

Triform is fortunate to be able to balance its annual budget through fundraising, the amazing generosity of our donors and tight budgetary controls. We are pleased to share that there is no tuition increase for the coming fiscal year. The Board of Directors of Triform Enterprises has approved an annual tuition of $60,765 for the year July 1, 2015 to June 30, 2016.

Triform depends on fundraising to help meet operating needs, including financial aid, and to raise money for capital projects. Tuition, however, is Triform's primary source of revenue. When a resident leaves unexpectedly during the course of the year, the lost tuition revenue cannot be immediately replaced. We must not allow unscheduled departures to jeopardize the financial health of Triform.

Most private secondary schools and colleges require tuition to be paid a semester in advance. Triform recognizes the financial hardship this would create for many families and will not deviate from our present monthly payment schedule. But commencing with the new school year in July, 2015 Triform's Enrollment Agreement for 2015-2016 will require parents to commit to a full year's tuition in the event of a voluntary withdrawal from Triform. This would not apply in the instances where a student is asked to leave for reasons of compatibility or behavior. In the case of a financial emergency or unanticipated hardship, Triform will consider each situation individually.

We trust that parents and guardians understand the need to protect the financial health of Triform, which in turn will provide an even better quality of life for your children.

Respectfully,

M Henderson

Meg Henderson
President

Valeska Davis

Valeska Davis
Chief Financial Officer

Stay + Safe

20 Triform Road, Hudson, NY 12534
(518) 851-9320 (phone), (518) 851-2864 (fax), information@triform.org (email)
www.triform.org
Triform, a Camphill Community including young adults with special needs, is a member of the Camphill Association of North America, and is a non-denominational community which does not discriminate on the basis of race, color, creed, gender or national origin. Triform is a not-for-profit organization. All contributions are tax deductible.

120x

TRIFORM
Camphill Community

20 Triform Road
Hudson, New York 12534
Phone: 518-851-9320 Fax: 518-851-2864
www.triform.org email: admissions@triform.org

STUDENT OPPORTUNITIES

Introduction

Triform's educational and vocational curriculum is designed to help each individual find meaning and direction in life, develop work and social skills and to make steps towards independence. Diverse academic and artistic courses, coupled with work training in a variety of on-campus settings, stimulate the capacities for independent thoughts, feelings and deeds, leading the individual towards maturity and self-discovery.

Morning student Work training Program: In the course of a year, students work and learn in two or three of the following work areas, five mornings a week. Specific tasks depend on abilities and interests of the individual:

1.) **Farm:** Triform practices biodynamic and organic farming methods of farming that restore the vitality of the soil, while providing nourishing food for the community. The areas that are covered in the farm work area include animal husbandry, small dairy hygiene, milking, field and fence work, machine maintenance and repair, haying, barn chores, and care of the environment. Tasks will include:

- Learning to observe the animals for health / illness
- Feeding and watering of the animals
- Cleaning / mucking out
- Herding cows / steers
- Milking cows
- Maintaining a clean and tidy milk room

2.) **Garden and Estate:** Planting and harvesting fruits and vegetables and herbs help young people acquire a sense of responsibility for the environment and for each other. In this block, the student will be active in seeding, transplanting, weeding, harvesting, vegetable storage, wood lot management, wood splitting and stacking, lawn mowing, and care of the environment. Tasks will include:

- Identification of trees and shrubs
- Understanding plant life cycle
- Work safety
- Identification, care and use of estate tools

- Woodlot management
- Firewood - splitting, stacking and delivering
- Landscaping - planting, weeding, watering aesthetics
- Identification, care and use of greenhouse tools and equipment
- Basic seed handling and starting seedlings
- Transplanting techniques
- Identification, care and use of garden tools
- Weeding and harvesting vegetables / flowers / herbs

3.) **Bakery:** The bakery provides bread, cookies, granola, and pizza for the community meals. The student is able to see the immediate results of his labor at their daily munch meal and tea breaks. Activities include - bread baking, general baking, and bakery hygiene. Tasks include:

- Identification of all bakery tools
- Identification of regularly used ingredients
- Learn acceptable standards of hygiene
- Adequately washing / drying of dishes, counters, floors, and tools
- Learning the proper place for all foods and tools
- Oiling of bowls and pans
- Chopping of nuts and dried fruits
- Learn to access all bulk items, i.e., work bins and spouts
- Keeping bins and containers full
- Discern water temperature by touch
- Work timer
- Learn bakery safety, including the operation of the fire extinguisher
- Learning to operate the oven

4.) **Home Economics Apprenticeship:** Learning how to keep and maintain a beautiful home and plan and create meals is central to life. The learning in this area is most important in teaching independence and self-reliance. Activities include - meal planning and preparation, food processing (canning and freezing), kitchen hygiene, housekeeping and ironing. Tasks include:

- Becoming familiar with the kitchen layout
- Correct storage and placement of kitchen utensils and ingredients
- Correct use of utensils
- Personal hygiene appropriate for kitchen work
- Cleanliness and order in kitchen
- Preparations of morning tea / coffee break for an average of 25 people (making coffee, tea, setting up dishes, etc)
- Clean up
- Setting the table (with care and completion), learn appropriate dishes / cutlery for various foods

- Proper washing, skinning, peeling, cutting, etc of vegetables
- Basic measuring and weighing
- Following simple recipes from start to finish
- Basic ironing and laundry skills; kitchen laundry and ironing

5.) The Weavery: The weavery is a training workshop, not a production shop. However, from time to time products are sold. The activities for this block include weaving, felting, sewing, various fiber arts and crafts. In this block the student will:

- Practice basic weaving skills / plain weaving with no pattern
- Learn to work with fleece in steps (teasing wool, washing / drying wool, carding wool with a drum carder)
- Learn to dye fabric
- Participate in fairs where Triform weavery has a table
- Clean / maintain looms and weavery room

6.) Pottery: The Triform Pottery produces useful and beautiful vessels for use in our houses and for future sale. The students participate in all aspects of the craft, transforming soft clay into durable ceramics. Some of the tasks involved are:

- Preparation or "wedging" of the clay
- Construction by pinch pot and coil methods
- Slab rolling and "slump forming" over plaster molds
- Finishing work on the electric potter's wheel
- Loading the kiln for a "bisk" fire (after air drying)
- Application of color and transparent glazes followed by a final glaze firing
- Care of tools and equipment, daily and weekly clean up of studio space

The Afternoon Education Program: The course work brings about the possibility for the student to have a creative experience of what they can do with their body, heart and mind. There are two courses each afternoon four times a week. The courses are selected each year and held in four to six week blocks. Some of the course work includes:

Painting
Eurythmy
Singing

Speech
Bells
Lyre (small harp)
Foreign languages
Current events
Conversation

Form drawing
Hand writing
Money management (tutorial)
Reading (tutorial)
First aide
Social skills
Story telling
History
Drama

Weaving
Clay modeling
Basketry

Wood carving
Bread making
Spacial dynamics
Dancing
Horseback riding
Movement

Tutorials: Individual and small group tutorials may be offered for those people who are able to continue their learning in the areas of math and reading. Triform also arranges classes with Questar for those students who wish to obtain a GED.

Community Events: Students are given the opportunity to participate one afternoon a week in the local community. Shopping, recycling, dining, attending plays or museums are among some of these activities.

June 9, 2015

Edward J. Pittarelli
3 Humphrey Drive • Park Ridge, N.J. 07656
201 307 1959 epittarelli@verizon.net

Robert Gordon
Chair
Senate Legislative Oversight Committee

Re: New Jersey Statewide Transition Plan Meeting June 10, 2015

Dear Senator Gordon:

I would like your help in keeping the State of New Jersey from making a misguided decision on housing for the disabled as part of the proposed New Jersey Statewide Transition Program that was submitted to the Federal Government's CMS organization. This proposed plan imposes restrictions far beyond those required by CMS and will have a significant negative impact on the disabled population. The restrictions will also cause the need for a significantly larger expenditures of funds to support the population than would be required if the group home size and disability restrictions were eliminated.

As someone who has been volunteering time to work with persons with various disabilities for over 40 years and is very active in the support of the autism community today, I am very cognizant of the needs of this population. These needs are very individual and do not lend themselves to a one size fits all solution. The restriction of group homes limited to 4-6 people will make the cost of providing reasonable services excessive in that many of the people in this population require 24 x 7 support, a significant portion have medical needs to be met. In addition, there are many behavioral issues to be addressed in the autism segment of the disabled population. Doing this effectively and efficiently requires that either residences be bigger or homes be clustered. The second misguided restriction that the State of New Jersey has proposed is to limit disabled persons to 25% of any residential facility, so the clustering or bigger size is effectively banned. The ideal facility for many of this population looks like either a cluster of residences such as exists in Allendale, New Jersey. This cluster, Orchard Commons, has

June 10, 2015
To whom it may concern:

As a parent of an adult with an intellectual/developmental disability (I/DD) and co-occurring medical issues and President of the Family Support Coalition of NJ (FSCNJ), I would like to thank the members of the Senate Legislative Oversight Committee for this opportunity to comment on the Home and Community Based Statewide Transition Plan (STP) submitted to the Center for Medicare/Medicaid Services (CMS) by the Department of Human Services (DHS) and the move to a fee-for-service provider-reimbursement system by the Division of Developmental Disabilities (DDD). Members of the FSCNJ consist of families who are caring for a family member with I/DD and provider agencies who serve individuals with I/DD throughout the state.

Statewide Transition Plan

The process by which NJ drafted, wrote, and revised the STP was completed without full engagement of stakeholders. While the minimum public comment period required by CMS (30 days) was allowed for by NJ DHS/DDD, the true spirit of stakeholder involvement in the process was not honored. DHS provided one 30-day review period and 2 public comment sessions (conducted during the day limiting many stakeholders from attending). Many states actively engaged stakeholders in the drafting of multiple drafts of their STP for up to 1 year prior to the March 17, 2015 due date demonstrating a sincere effort to understand the needs of those who served under the STP. New Jersey DHS/DDD include families or providers in the writing of the draft STP. The FSC submitted comments (attached) on February 24, 2015.

New Jersey allowed less than 30 days for stakeholders to review the draft STP. Despite an enormous outpouring of comments from stakeholders at the public hearings and more than 1,300 written public comments (primarily negative feedback and grave concerns about the restrictive nature of the STP) on the draft STP, the revised document was submitted to CMS without further opportunity for any stakeholder input. In fact, DHS/DDD requested a 30-day extension to revise the STP and the final document was submitted on April 17, 2015 without further stakeholder input.

While the final STP addressed some comments, there remain a number of significant concerns about the submitted version. One of the more critical issues is the 25% density rule for residential settings. The STP was revised to clarify that new development of community based housing developments will require that no more than 25% of the residence be set aside for individuals with I/DD. This requirement seems to be arbitrary and may violate the rights of individuals with disabilities to live where they choose. New housing options must comply with the not taking into account medical/behavioral challenges of some individuals or provide meaningful community activities. We are encouraged by this revision and hopeful that DHS/DDD will continue to work with providers of day services in creating more flexibility to meet community integration goals while honoring individuals' person-centered plans.

Lastly, there were numerous requests from stakeholders that DHS/DDD establish a stakeholder advisory group to participate in ongoing discussions on critical issues and concerns, particularly as these new initiatives are implemented. Every aspect of the STP must be carefully and thoughtfully reviewed by policy makers, service providers and, most importantly, the recipients of services and their families. The FSC would like to ask that such an advisory group of stakeholders be established to monitor the implementation of the STP over the next four years.

Fee for Service

Families and providers have many reservations that the Fee-For-Service (FFS) system is ready or able to make the switch in a thoughtful and efficient manner beginning in July 2015. Prior to the past 6 months there was limited outreach to persons with I/DD and families as well as provider agencies to educate or prepare them for this transition. With less than a month to July 1, stakeholders are experiencing high anxiety levels about the impact on our most vulnerable citizens. Concerns cover a wide range of issues remain, among them the lack of stakeholder review and input on the new NJ Comprehensive Assessment Tool (NJCAT) which has not been validated for the I/DD population. Families do not know the intent of changing the assessment or the specific changes in the content and scope of the NJCAT. Specifically, how does the NJCAT take into account specific medical issues, such as epilepsy, physical disabilities, and behavioral health and the nuances in independent living that are not captured in a single assessment tool.

The division anticipates estimated 30,000 individuals will be reassessed using the NJCAT by this fall. With the first notices to individuals to complete the NJCAT mailed on April 1st, families are experiencing delays in receiving responses from the Developmental Disabilities Planning Institute (DDPI) delaying their ability to complete the assessment. Some families have waited up to 3 weeks for a reply and have only limited communication as a result their follow-up. After reaching out to DDPI, some families have received the following email from DDPI: "Thank you for contacting us. We appreciate you following up on your assessment. We are currently receiving a high volume of "NJCAT needed" emails, calls and voice messages. These requests are very important to us and we are currently working on creating a survey for you. We will send you the

While DDD provided the 140-page draft Supports Program Policy & Procedure Manual to stakeholders for review, we had only 17 days to review the document. DDD has stated they will continue to take and review comments while discussion and revisions are ongoing. We hope this is honored as some comments on the initial draft were not addressed in the second version.

The incompleteness of the SP manual is evident from a number of notes/footnotes and highlight the need for more information and movement on amendments to the SP including:
"The Division is working to amend the waiver to read that the individual needs to be "at least 21 years of age" in order to enroll individuals into the Supports Program prior to graduation."
"The Division is working to amend the waiver to allow individuals who require private duty nursing to access that service from a MLTSS program and still remain on the Supports Program."

Like other stakeholder organizations, the FSC has requested that a working committee be formed to assist in future review and revision of the manual as well as developing a shorter more user friendly guide for families. It is essential all individuals and their families clearly understand all policies and procedures under the waiver, most importantly their roles and responsibilities.

Certain policies within the current SP manual do not mirror the current self-directed service system that has been used in recent years. In the current (as of today) system individuals could access the funds in their budget throughout the year, reflecting real life where needs can change from hour to hour. Under the new system, families will need to assign money for each service in weekly allotments based on anticipated need. If for some reason that service is not used in the prescribed time period, the funds will be not available at other times during in the year regardless of need. A service or services may not be needed or feasible depending on life circumstances at any given time. For example, a parent may be stuck in traffic and need the direct support professional (DSP) to stay another 1-2 hours, the DSP is ill and cannot take individual out as scheduled, DSP cannot get to home due to inclement weather, work schedule changing from one week to next over a weekend pushi ng into the next week. There is no flexibility in current model to allow for these unexpected events. The individual should not lose funding/service due to circumstances they cannot control. Annual budgets must allow flexibility for individual/family to meet daily needs and for funds to be redirected as needed throughout the year. Individuals and families should be able to keep unspent money in their budgets and redirect it as needs arise and change throughout the year.

Hillsborough, NJ 08844

Family Support Coaltion

Subject: HUMAN SERVICES - DEVELOPMENTAL DISABILITIES

132X

Written Testimony

Submitted via E-mail By

Dr. Michael D. Cole

133X

To: New Jersey Senate Legislative Oversight Committee
Testimony Submission Dr. Michael D. Cole 6/10/2015

The Department of Developmental Disabilities has characterized the negative reaction by families impacted by the Return Home New Jersey program as being driven by fear of change. This is unfair and inaccurate. I offer my sister's case as one example of why this program is harmful when case specifics are reviewed.

Jane Cole Background

- My sister Jane was brain damaged at birth and has a functioning level of a 7 year child. My parents were her caregivers at home. They both died in the 1970's and I became Jane's guardian.
- The Department of Mental Retardation (DMR) of New Jersey (as it was known then) arranged placement for Jane in a group home in Woodbury N.J. After visiting the group home I became concerned about its lack of oversight and structure for someone as vulnerable as Jane and expressed this concern in writing to the DMR in April 1980. I was assured that steps would be taken to safeguard Jane's health and safety.
- Tragically, her safety was not safeguarded and she was the victim of a sexual assault two months later. Jane was traumatized and I was also in shock feeling extremely sorry that I listened to the assurances of the DMR who were highly apologetic after what occurred. Jane's client manager at the time (Ms. Ellen Sears -now deceased) out of a spirit of regret and restitution for Jane's awful Woodbury experience was able to secure an opening for Jane in an out-of- state placement at Riverbrook in Stockbridge, Massachusetts.
- That was 35 years ago. After a period of adjustment, Jane has thrived at Riverbrook (which is now her second extended family). She is connected to the community through her church and her work, and feels like an important person in the Riverbrook and Stockbridge community. I visit her frequently and she comes home for holidays and various family events. The drive time from Bergen County is not much more than the drive to Woodbury, N.J.
- In August 2014 I received a form letter from the Department of Human Services (Carrie Conger) informing me that Jane will be moved back to a placement in New Jersey as part of the Return Home New Jersey program.

I was appalled. After 35 years, a 65 year old mentally disabled woman is to be uprooted from a home she has been so happy in with all of its support systems and community connections, and be moved to another place far away, especially after what happened to her at Woodbury. As her brother and guardian I could not let this stand.

Impact of moving Jane after 35 years

- Relocating Jane will have severe negative impact on her. In October 2014 Jane received a comprehensive psychological evaluation. The finding: moving Jane would be traumatic for her and her memories of her prior New Jersey placement are of "... *great volatility, tumult, and discord. When she discusses her time there, she experiences high anxiety. She also expresses high anxiety by having to live anywhere besides Riverbrook".*
- Jane's psychiatrist of over 10 years determined that moving Jane puts her at "*high risk*" and that relocating Jane would cause her to "*suffer depression and decline…from which she may never recover*".

Financial Rationale for Moving Jane

- Part of the rationale used for Return Home New Jersey is financial. Under the latest contract New Jersey annually pays Riverbrook $57, 346. Including some incidental expenses the total may approach $63,000. I now contribute $9216 annually (which is most of her Social Security benefits), so the net cost to New Jersey is about $54,000 annually.
- I am told by DHS sources that the average cost per resident in New Jersey is $110,000-120,000. Where's the savings? Even with the cost sharing arrangements available through the Fed, it will cost New Jersey taxpayers more to bring her home.

Interaction with the NJ Department of Human Services

- In September 18, 2014 I wrote to New Jersey Department of Human Services Commissioner Jennifer Velez about this situation and followed up with correspondence to her on October 2, October 18, and October 26. **Ms. Velez resigned in February 2015. An acting commissioner Elizabeth Connelly now fills the position.**

- On November 12 I received a formulaic response from the office of Carrie Conger who as Director was responsible for the Return Home New Jersey program. I met with Ms. Conger earlier this year. She was quite sympathetic to Jane's situation but felt she had limited administrative authority to exempt Jane from RHNJ. **Carrie Conger left her position last Friday, June 5.**

- The State of New Jersey has contracted with an organization called Caregivers of New Jersey to implement the Return Home New Jersey program. On November 20, 2014 one of their representatives assigned to my sister's case, Craig Heck, visited Riverbrook and met my sister. I attended that meeting. He produced a summary report which included Jane's recent psychological evaluations which recognized the traumatic impact that relocating Jane would have, but he too had his organizational orders to implement the program. **Craig Heck resigned from his position this May 2015.**

- On March 24 2015 I met with Deputy NJ- DHS Commissioner Dawn Apgar, Ms. Conger and DHS Attorney Carol Jones. Ms. Apgar's summary of the situation was:
  "Everyone's coming back"; she and her department are not willing to apply any evaluative criteria to the New Jersey clients outside of the state. "Everyone has a story" and she doesn't want to be in the position of making judgment calls on who should stay in their placement regardless of the circumstances. Her position is that *unless the legislature changes the ground rules, she's moving everybody back.*

- In Jane's specific situation, Commissioner Apgar's three positions were:
  1) *While it was true that my sister was sexually assaulted at her last NJ group home placement (which was "unfortunate") that was over 30 years ago and Commissioner Apgar is confident that today's facilities in New Jersey are very good and Jane would be safe there.*

I participated in a phone "meet and greet" for a group home bidding for Jane as a resident. Their building is not complete and they have no staff in place yet. The woman who participated in the call was a nurse who had limited professional credentials in disabled care and had no knowledge of my sister's background. I then received a proposal from this organization complete with job descriptions for staff that have not been hired yet, and an overview of their programs which are not in place.

I did due diligence on that company (EIHAB) and discovered that they were sued in New York because one of their residential clients was abused and nearly choked to death while being supervised by a "teen employee". The client had long-term negative health repercussions because of this and apparently was also subjected to harsh physical treatment by the staff at EIHAB resulting in bruises and abrasions. EIHAB was also charged with falsely billing Medicaid for five years for clients that were not present. They settled for $54,000 with New York State and $36,000 with the US. Among the allegations were that a case manager was ordered to fabricate case notes and documents to substantiate billings (see attachments).

I called Ms. Conger to give her a "heads up" on this situation. She told me that she was aware of EIHAB's background, but what happened in New York has no bearing on happens in New Jersey.

How can I as a guardian allow my sister to be put in a situation such as this—again!

2) *Although the annual net cost for Jane at* <u>*$54,000*</u> *is much less than a New Jersey placement, Commissioner Apgar feels there is a risk if some out-of-state clients are granted the ability to stay out of state, the out-of-state providers could "hold New Jersey hostage" and raise their fees precipitously.*

New Jersey has been negotiating annual contracts with Riverbrook for 35 years. If Riverbrook was to unjustifiably and precipitously raise their rates, as in any business transaction, New Jersey would have the right to propose alternatives.

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3) *Moving Jane after 35 years may seem dramatic but DHS just moved a client back to New Jersey after 47 years out-of-state (he had started there at three years old) so Ms. Apgar did not feel the transition issue was serious enough to stop her from moving back all the clients.*

This is clearly a "one-size-fits-all" approach-- perhaps the client that Commissioner Apgar mentioned was happy to move to another location or may not even have been aware of it depending on his medical situation. My sister has been given in-depth evaluations that show a move like this would be devastating for her at her age.

Legislative Actions

- In June 2014 a bill was nearly unanimously passed by the NJ Legislature (S2249) that would have placed a moratorium on the Return Home New Jersey program and exempted out of state placements who had been residing there for significant time. In August 2014, the bill was given a conditional veto by Governor Christie. Since that time there have been efforts in both houses to come up with a solution that would provide exceptions for those who would be harmed by a move back to New Jersey at this point of their life.
- The efforts in the legislature to arrive at a reasonable solution continue and since there is no chance of administrative remedies from DHS one hopes that the N.J. Legislature can put aside party differences and develop a reasonable solution with the support of the Governor's office.

Summary

As I become more knowledgeable on this topic it's clear that there are many problems with the Return Home New Jersey program. I've had the opportunity to meet other parents and guardians who have profound issues, for example a level of medical care needed by their loved ones which is not available in New Jersey. There are literally thousands of disabled people in New Jersey waiting for placement in a residential facility in the state and yet the focus is on moving back disabled people who are already successfully placed. What seemed like a financial opportunity for New Jersey at a macro level due to Fed cost-sharing breaks down when case specifics are considered, and in many cases the potential costs in human terms are appalling.

I believe that the Return Home New Jersey program is problematic and should be stopped, reviewed, and closed or at least re-structured.

Sincerely,

Dr. Michael D. Cole
201-741-5960
mdcfree@earthlink.net

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Qui Tam Whistleblower Medicaid Fraud Legal NEWS

McInnis Law
Timothy J. McInnis, Esq.
521 Fifth Avenue, 17th Floor
New York, NY 10175-0038
212-292-4573 – 917-903-9424
www.WhistleblowerLegal.com
TMcInnis@McInnis-Law.com

FOR IMMEDIATE RELEASE
March 5, 2013

New York Non-Profit Serving Developmentally Disabled Children and Adults Settles Whistleblower Complaint Alleging False Billing at Queens and Brooklyn Day Habilitation Centers

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(New York City) — A non-profit serving the developmentally disabled in three states falsely billed New York State Medicaid for day habilitation client services for five years even though its own attendance records showed some developmentally disabled clients were not present, according to allegations in separate whistleblower settlements between the provider and New York State and federal governments, Manhattan-based Qui Tam Whistleblower Attorney Timothy J. McInnis of McInnis Law announced.

EiHAB Human Services, Inc., ("EIHAB") headquartered on South Conduit Avenue in the Springfield Gardens section of Queens, New York, falsely billed the governments for day habilitation according to the settlement agreements. While not admitting liability or conceding that the governments' and the relators' claims were well founded, EIHAB paid $54,000 to New York State and $36,000 to the United States. In addition, EIHAB was required to retain a compliance monitor approved by New York State who will send quarterly reports on the non-profit's services billed to Medicaid, according to the agreement.

McInnis, a former federal prosecutor whose law practice serves whistleblowers across the country, originally filed the EIHAB Qui Tam Complaint in early 2010, under seal as required by federal and state False Claims Acts.

McInnis's clients are two women who held management-level positions at EIHAB. They are identified in the Complaint only as Mary Roe and Jane Doe. Among allegations in the Amended Complaint, all of which were dismissed in the stipulation of dismissal unsealed with the Amended Complaint, are that EIHAB ordered a case manager to fabricate case notes and other documents to substantiate billings that also were needed for a 2009 audit. That false data was in turn sent to the New York State Office of Mental Retardation and Developmental Disabilities, ("OMRDD") which licenses and regulates habitation services, it was alleged.

(More)

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Among many services EIHAB provides in the Empire State in addition to habilitation at centers in Brooklyn and Queens are: residential services; Medicaid Service Coordination ("MSC"), which helps beneficiaries to receive entitlements and services from the program; respite services; and family support services.

EIHAB's annual revenue was estimated at $10 million or more. Day habilitation services fees were estimated at approximately $1.3 million per year. Almost all of EIHAB's annual revenue is from Medicaid, according to the Amended Complaint. EIHAB provides group home services in New Jersey. In Pennsylvania it offers 12 different services, including those provided in New York, along with a summer camp.

The organization also solicits donations on its website. Web visitors who donate at http://www.EIHAB.org/donate[1], can charge their gifts to one of four major credit cards or use their PayPal account.

That page features a quote from Victor Hugo, "As the purse is emptied the heart is filled." Under a "Donate Today" headline it states, "Your donation to EIHAB provides life-enhancing services for people in need right in your community. With your assistance we help physically and mentally challenged individuals lead more meaningful, dignified and independent lives."

"They tried to empty the wrong purse at EIHAB," McInnis said, "taking money from New York State's and federal taxpayers' pockets by falsely billing for service they didn't provide to their vulnerable day habilitation clients."

After he took over as billing manager in 2004, the son of EIHAB's Executive Director Fatma Abboud, "maximized the billing units regardless of the nature and scope of the services actually provided." The new billing manager and his fiancée also shredded records and created other "sanitized" billing records to support the false claims, the Amended Complaint alleged.

Under the False Claims Act, Qui Tam actions allow private citizens with knowledge of fraud to help the Government recover ill-gotten gains and additional civil penalties. The FCA allows the Government to collect up to three times the amount it was defrauded, in addition to civil penalties from $5,500 to $11,000 per false claim.

In successful Qui Tam whistleblower cases in which the Government intervenes, whistleblowers are typically entitled to receive awards representing 15-to-25 percent of Qui Tam recoveries. However, in cases where the allegations are not resolved and are taken to trial by the relator, the relator's share increases to 25-to-30 percent. In this case the relators received 20 percent, McInnis explained.

(More)

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[1] Visited March 4, 2013

“The federal False Claims Act and its qui tam provisions have returned billions to taxpayers since the “Lincoln Law” was strengthened in 1986. Many states and two cities enacted their own versions after that,” McInnis said.

“This case is another example of motivated citizens stepping forward to, ‘Do the right thing,’ by reporting false billing when the government pays for goods or services that never were delivered. While rewards in outlier whistleblower cases can be substantial, my clients have received the most important reward all whistleblowers want from their cases, correcting billing abuses by employers who won’t.”

This case was assigned to United States District Court Judge Raymond J. Dearie, in the Eastern District of New York, who approved the settlement.

Docket Number, U.S. District Court, Eastern District of New York: Civil Action No. 10- Civ. 0898 (RJD) (SMG).

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Contact:
Timothy J. McInnis, Esq.
McInnis Law
212-292-4573
TMcInnis@McInnis-Law.com

This news release and related filed documents are posted in the “Successful Cases” Section of WhistleblowerLegal.com.

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ADDITIONAL APPENDIX MATERIALS
SUBMITTED TO THE

JOINT COMMITTEE ON THE PUBLIC SCHOOLS
for the
June 10, 2015 Meeting

Submitted by Theodore Kastner, M.D., President, Developmental Disabilities Health Alliance, Inc.:
Sandra L. Decker, "Two-Thirds of Primary Care Physicians Accepted New Medical Patients in 2011-2012: A Baseline to Measure Future Acceptance Rates," *Health Affairs,* 32, no. 7 ((2013): 1183-1187, © Project Hope.

Submitted by Leslie Meril, Private Citizen:
Division of Developmental Disabilities, Department of New Jersey, "Return Home New Jersey," www.state.nj.us/humanservices/ddd/programs/rtnhomenj, © State of New Jersey, 1996-2008.

Submitted by Michael D. Cole, DPS, Private Citizen:
Matt McNulty and John Marzulli, "Brooklyn group home nearly killed severely autistic patient, says parents' lawsuit," *New York Daily News,* July 18, 2012.