



PLAN|NJ NEWS

THE NEWSLETTER OF PLANNED LIFETIME ASSISTANCE NETWORK OF NEW JERSEY
FUNDED BY THE NEW JERSEY STATE BAR FOUNDATION

SPRING 2015

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INSIDE THIS ISSUE:

Christina's World	1
Annual Report Available	1
Wilson and Wood Join PLAN/NJ Board	1
Medicaid & DDD	2
PLAN/NJ Website	4
Donate Via AmazonSmile	4

PLAN/NJ ANNOUNCES COMPLETION OF ANNUAL REPORT

The PLAN/NJ Annual Report for 2014 has been published. Features include a diagram of the PLAN/NJ Service Model; descriptions of PLAN/NJ programs, services, educational seminars; recent accomplishments; a list of our foundation supporters; messages from Board President Regina Tegler and Executive Director Ellen Nalven; and more. To view a copy of the annual report, visit www.plannj.org and scroll down. If you would prefer a copy sent to you, either via e-mail or hard copy, please contact lynn.martorano@plannj.org or the main office at 908-927-9006.

CHRISTINA'S WORLD

Perhaps you are familiar with the famous 1948 Andrew Wyeth painting "Christina's World." The painting has muted colors, a barren landscape, and features a woman named Christina who has a physical disability. She is painted wearing a worn-out dress, crawling in a field trying to get back to her home because she does not have the use of her legs. Showing struggle and pain, the painting is in complete contrast to the world of the Christina Planned Lifetime Assistance Network of New Jersey (PLAN/NJ) knows and cares for.

Our Christina's world is filled with purpose, meaning and a love of life. Although she does have a disability, it does not limit her life. High-spirited and with a fashionable haircut and blonde highlights, our Christina wears stylish glasses and prefers jeans, sweatshirts, and sneakers to a dress. She is a huge fan of the movie *Frozen* and enjoys movie outings with Nadine, her PLAN/NJ service coordinator. Christina and Nadine go on many adventures together, enjoying skating, musicals, and animal shows. Christina also uses her exercise bike, goes to the gym, and even has a trainer to keep her healthy. Although Christina has little family, she knows that PLAN/NJ is her surrogate family. We encourage her to have a social life with friends from her group home and day program.

Our Christina is sweet and friendly and is a great advocate for herself, informing Nadine during her home visit monitoring sessions if she needs or wants anything. PLAN/NJ works to



keep Christina's world full of options. She loves animals, especially cats, and is currently working on her group home's quarterly newsletter, for which she is in the process of creating a new section highlighting stories of pets that need to be adopted.

Perhaps Christina's life would be more like the Andrew Wyeth painting if PLAN/NJ was not there to assist. But instead of struggling, Christina is free to contribute to her life with gusto. PLAN/NJ is proud to know Christina and we will be there for her always, ensuring that instead of discomfort and insecurity, she is free to enjoy her life with no limitations.

Wilson and Wood Join PLAN/NJ Board



Adam
Wilson,
Esq.



Kathleen
Wood

Adam Wilson, Esq., and Kathleen Wood have both been named to the PLAN/NJ Board of Directors. Visit plannj.org for more information on these two extraordinary individuals.

Medicaid & DDD: Change Is In The Air

By Shana Siegel, Esq., of WanderPolo & Siegel

The only constant with Medicaid over the last several years seems to be the constant change. This has only escalated in the last two years as nearly every aspect of Medicaid has endured change. This article will provide an overview of the Medicaid reforms that impact individuals served by the Division of Developmental Disabilities and the underlying reasons for these changes. We will also consider what to expect over the next several years as the state works to comply with new Medicaid rules.

Link Between Medicaid and DDD

While DDD services were historically funded partially by Medicaid, it was not until 2013 that the state required individuals receiving DDD services to secure Medicaid eligibility. This has proven problematic for many individuals with disabilities who were not receiving SSI or Medicaid. The advocacy community has done substantial education and outreach to ensure that individuals who can become eligible for Medicaid do so, either through SSI, DAC (disabled adult child) status, or Medicaid programs such as Workability. The state has also recognized a process for non-DAC eligible individuals to continue to receive DDD services for now. This remains a policy issue that needs final resolution so all individuals who meet DDD criteria can continue to receive services they need.

The linkage of Medicaid and DDD was a prerequisite for the Division's move to a fee-for-service reimbursement model. Previously, DDD services were largely provided through global contracts with providers. For instance, a day program or group home would have a certain number of slots and would receive a flat rate for each participant. However, because of the complexity of the Medicaid system and the wide variety of funding streams available and changing rates over time, there was no uniformity in rates or services covered.

Fee-For-Service Model

The new system will implement fee-for-service reimbursement so that a provider will receive payment for each service provided to a beneficiary. For example, a day program may include employment, behavioral, and community inclusion services, and under the new system these services (whether provided by one or

multiple providers) will each be separately billed. In theory, this is advantageous because the beneficiary will receive individualized services. The billing is also meant to allow individuals with less need to receive some services. It is true that the current system is more of an all-or-nothing approach that leads to under-serving some and over-serving others. However, a fee-for-service model is quite complex, with each service requiring approval. By looking at the new DDD Supports Program, we can understand how the fee-for-service model is supposed to work and its potential advantages and disadvantages.

Supports Waiver

When the Fee-for-Service System is implemented (currently scheduled for July), adults enrolled in or seeking DDD services will have to be enrolled in one of two Medicaid waiver programs: the Supports Program or the Community Care Waiver. The Supports Program is a Medicaid waiver program for adults who live in a non-licensed setting to access DDD services such as day programs, assistive technology, and supported coordination. The theory is that the program will allow those with less need to receive fewer or less costly services, thereby reducing the waiting list for higher levels of services. The obvious danger is that the program will be used to cut services to individuals for fiscal reasons.

Every individual receiving Division services will be assessed using the New Jersey Comprehensive Assessment Tool (NJ CAT). This tool will be used to determine an individual's needs, their "tier" for rate-setting, and an individualized budget for the "purchase" of needed services. Therefore, this assessment is a key opportunity for advocacy by the beneficiary and their family members.

Although the supports program is fee-for-service based, care coordination is an important component. Each beneficiary will work with a support coordination agency that will help develop an individualized service plan. Under the Supports Program, case management will move from the Division to private support coordination agencies. These agencies will not deliver direct services, instead focusing on case management. The state has determined that these agencies cannot specialize in a particular population

or disability but must serve all beneficiaries. Another, more troubling, policy decision was made by the Division not to set maximum caseload ratios.

Theoretically, the support coordinators within the agencies are to work directly with consumers to help them find providers and facilitate decision-making by consumers. While this is a noble ideal, it is hard to see how anyone but the most savvy consumers will have the knowledge to decide between providers. The program also reflects a greater emphasis on employment goals and community integration. Every ISP must include an employment goal regardless of the feasibility of employment for the individual. In addition, community integration is a key requirement for all participants.

Once a service plan is developed, it must be approved by supervisors within the support coordination agencies. The agency is then tasked with monitoring the service plan with quarterly face-to-face meetings and annual home and setting visits. Again, this provides an opportunity for family involvement and advocacy. With support coordination agencies playing such a key role, it is important to make an informed choice in choosing an agency. The Boggs Center on Developmental Disabilities at Rutgers has prepared informational materials on selecting a Support Coordination Agency (available at <http://rwjms.rutgers.edu/boggscenter/products/documents/ChoosingaSupportCoordinationAgencyfinalApril2014.pdf>).

There is less known about how and when the Community Care Waiver will incorporate support coordination and individualized service plans. For now, CCW will continue to serve individuals with more substantial functional limitations who need a higher level of services. It seems likely that individuals with less perceived need will be switched to the Supports Program in order to serve the stated goal of reducing the CCW waiting list. All beneficiaries, including those on CCW, are in the process of being reassessed, so it is important to be prepared. The Division has stated that it is projected to merge CCW into the Support Program over a number of years.

Services Not Included

Another important issue is that housing and transportation services are now

unbundled (instead of being part of a flat contract rate) and will have to be billed and funded separately in many cases. This is a major issue that the state has been remarkably silent about and is certainly a major “kink” to be worked out between agencies to ensure community placements are not put at risk.

There has also been great concern about how individuals who need extensive nursing services will be served. The Division and Medicaid have both indicated that individuals will not be allowed to enroll in one of the DDD waivers and MLTSS (managed long term services and supports). Therefore, consumers are forced to determine which program better fits their needs. This is especially problematic for individuals who receive substantial DDD services but require private duty nursing. This extensive nursing service is not covered under the DDD waiver or traditional Medicaid. The state has determined that individuals who previously received private duty nursing under CRPD (community resources for people with disabilities), which has now been consolidated under MLTSS, but are also enrolled in a DDD day program will be grandfathered in to continue to receive both services. This will undoubtedly be a recurring issue as the two systems evolve.

The Home- and Community-Based Services (HCBS) Federal Rule

In January 2014, the federal agency that governs Medicaid issued a final rule to ensure that Medicaid’s home and community-based services (HCBS) programs offer services in the most integrated settings and provide the highest level of autonomy and self-direction for consumers. The rule implements a system of person-centered planning that is designed to reflect individual preferences and goals. The final rule became effective March 17, 2014, and gave states one year to submit a transition plan for compliance with the HCBS setting requirements. New Jersey’s transition plan has raised serious concerns among special needs advocacy and support communities.

While New Jersey’s transition plan certainly has many flaws, which will be discussed more below, the ideals behind the federal rule can lead to meaningful changes for individuals with special needs. The support coordination and individualized service plan of the Supports Program are an outgrowth of the rule’s requirement for a person-centered planning process. The federal regulation requires that a customized

plan be developed to provide the services and supports an individual needs. The regulation requires the plan to meet with the consumer and whomever they wish at a time and place convenient to the consumer. The plan must incorporate the individual’s goals and preferences, including those related to community participation, employment, income and savings, health and wellness, and education. Perhaps most important, services cannot be cut without following the person-centered planning process.

The federal rule has substantial requirements regarding the integration of home and community-based settings in the larger community. This means that to avoid an institutional-like setting in HCBS programs, the programs cannot be clustered and segregated. For example, to encourage community integration, residential and day programs cannot be co-located. Settings that are provider-owned or controlled (i.e., not private homes) must allow for tenant protections, provide private units with lockable doors, allow for choice of roommate, and have no limitations on visitor hours. While these requirements can cause difficulty for some group homes and supported living models, they are meant to ensure that individuals with developmental disabilities remain in the least restrictive setting, encouraging mainstream community interaction beyond their school years.

New Jersey Transition Plan

The federal rule requires the states to provide a transition plan that outlines the steps the state will take to comply with the federal rule within five years. Many of the ideals behind the federal rule are encompassed in the comprehensive Medicaid waiver and the DDD Supports Waiver. The state indicated it needed to develop additional policy changes in its residential settings such as group homes and other supported living arrangements, as well as in its day programs in order to meet the federal requirements. Although the federal guidance was general, the state has proposed specific guidelines that many advocates and consumers find onerous.

For example, the federal rule indicates that HCBS settings must provide opportunities for individuals to live and work in an integrated environment and engage in community life with the same access to the community and housing options as people not receiving Medicaid HCBS. The state proposed complying with this standard by limiting new

congregate housing to no more than six individuals. It also proposed requiring settings that serve more than six individuals to be in a building where no more than 25 percent of units are set aside for individuals with disabilities. DDD also proposed providing a housing subsidy to consumers who choose to leave a licensed group home setting for an integrated community setting only be available to those in which no more than 25 percent of the units are set aside for people with disabilities.

The Division has proposed a major overhaul of day programs stating that the facility should serve as a central meeting location, but the majority of programming must be in the community in activities such as volunteering, training, and recreation. The Division has expressed a goal that individuals should spend the majority of their time in activities in the community that reflect their individual goals. The Division proposed that individuals should spend 75 percent of their time in outside activities, not at the facility. The state also proposes prohibiting multiple services for people with intellectual and developmental disabilities from being offered at the same site.

In an idealized world, the reforms in Medicaid and DDD would lead to great improvement in the lives of individuals with developmental disabilities. There is much to be hopeful about in the changes. Implementation of the federal rule can lead to greater protection, autonomy, and community involvement for participants. Moreover, the individualized approach envisioned under the federal rule and the Supports Waiver is a major step forward. However, there is much to be wary about as well. The à la carte nature of the program will allow for denial of services and cost-cutting. If rates are inadequate, then providers will not participate and quality programming cannot be maintained. In addition, some of the guidelines proposed by the state are not workable. Some individuals may not thrive if forced to fully integrate in the community. Moreover, the complexity of such an individualized system leads one to wonder if the state has bitten off more than it can handle. Only time will tell how this transition will evolve, but meanwhile consumers must stay informed and stay involved.

Shana Siegel, Esq. is the principal of WanderPolo & Siegel and the President of NJ NAELA.



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People with Differing Abilities*

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PLAN/NJ WEBSITE

An Abundance of Information

Have you checked out the PLAN/NJ website lately? It contains pertinent information for families, professionals, and other individuals with descriptions of our services, how to develop a LifePLAN, special needs trust information, and our fee schedule. If you visit the website, you'll see it also contains:

A printable version of our Professional Directory, a listing of professionals who have interest and experience in estate planning and many other related matters for individuals with disabilities and their families, including guardianship, public benefits, and special education laws.

A donation link — for a fast and convenient way to help support PLAN/NJ programs and services.

Links to state, federal, and community organizations dedicated to assisting families of individuals with disabilities.

Printable versions of various PLAN/NJ materials, including newsletters and brochures.

Photos of some of the many wonderful clients we assist, enjoying their lives.

Board profiles, client stories, links to articles, and more!

Simply visit www.plannj.org to start exploring and learning about PLAN/NJ today.

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