

August 10, 2016

Margaret Rose
Division of Medical Assistance and Health Services (DMAHS)
PO Box 712
Trenton, NJ 08625-0712

Dear Ms. Rose,

The Arc of New Jersey appreciates the opportunity to provide comments on the 1115 Comprehensive Medicaid Waiver Demonstration Application for Renewal. We thank the Department of Human Services for extending the initial comment period to allow our organization, and other stakeholder groups, to fully review and respond to the proposed Application. As you know, the Waiver impacts a number of populations and so we thank you for recognizing the magnitude of this document and the need for more time. With that said, The Arc of New Jersey would like to provide feedback on a number of areas mentioned within the application for renewal.

C. Providing Comprehensive Supports to Individuals with Disabilities

Pilot Program for Adults with I/DD and Co-occurring Behavioral Health Needs

We are very pleased to support the creation of a pilot program for adults with the dual diagnosis of intellectual and developmental disabilities (I/DD) and co-occurring behavioral health needs. We believe this addition reflects the necessity of developing and providing specialized services for an underserved group within our population who often struggle to obtain the behavioral health services and supports they require to live successfully in the community. Families and providers often tell us of their frustration and anguish in attempting to locate the behavioral health services that individuals who have this type of dual diagnosis urgently need. We applaud the Department's recognition of this important need and we would like additional details about the pilot program and its implementation. The Arc of New Jersey requests information on approximately how many individuals will be served via the pilot program as well as details on how supports would be designed to address the unique needs of this population. We look forward to more details on this in the near future. We also support the addition of an eligibility group (WorkAbility) in the Community Care Waiver Renewal and by placing the CCW under the Comprehensive Medicaid Waiver, the ability to add other eligibility groups in the future as the need arises.

Serving Children and Families with Comprehensive Supports

The Arc of New Jersey is supportive but would like additional information regarding the new Children's Support Services program that will expand access to services currently available

under the ID/DD-MI and ASD pilots as well the comprehensive package of services being developed for youth with autism as part of the Medicaid State Plan. Additional behavioral health services for youth with autism and intellectual disabilities are urgently needed, and we fully support this initiative. However, we would like assurances that the expanded behavioral health services that will be developed for individuals who receive Medicaid and are under the age of 21 will continue when they are age 21 and older.

D. Modernizing Eligibility and Enrollment

The Arc of New Jersey is concerned by the Department's proposal that would require individuals with intellectual and developmental disabilities who have Medicaid to enroll in Medicare Part D. Some individuals with I/DD who are Medicare eligible also have private health insurance through their parent's commercial health plan. Typically, these individuals do enroll in Medicare Parts A and B. However, if they are receiving prescription coverage from the parent's private health insurance, they are told *not* to enroll in Medicare Part D because that is viewed as "double dipping," and it could jeopardize the private insurance coverage. In these situations, most of their prescription costs are covered by the private insurance. Therefore, these individuals with I/DD should *not* be required to enroll in Medicare Part D.

E. Integrating Care for Dual Eligible Individuals

We are strongly opposed to language in the proposal that would require all individuals who are eligible for Medicare and Medicaid to be enrolled in a fully integrated dual eligible special needs plan (FIDE-SNP). Historically, this decision has been voluntary and determined by the individual and their unique situation and circumstances. We fear that the outlined plan would eliminate choice and options. There are a large number of individuals with intellectual and developmental disabilities (I/DD) who have both Medicare and Medicaid. It is essential that these dual eligibles and their families are able to choose whether it is better to be enrolled in Original Medicare and a Medicaid MCO, or in a FIDE SNP. For some dual eligibles with I/DD and their caregivers, having access to the wide range of doctors and hospitals who participate in Original Medicare is of paramount importance, and they should have the option to remain with Original Medicare – without being converted into a FIDE SNP and having to figure out how to dis-enroll. For other dual eligibles with I/DD, it may be more important to have the convenience of being enrolled in a fully integrated dual eligible (FIDE) special needs plan (SNP). We strongly support informing dual eligibles with I/DD and their caregivers about the option to enroll in a FIDE SNP, but it is not acceptable for dual eligibles with I/DD to be converted to the FIDE SNP managed care program.

For the reasons outlined in the above paragraph, we are also strongly opposed to FIDE SNP auto-assignment of anyone with I/DD who is becoming a dual eligible. We strongly oppose requiring dual eligibles with I/DD to be enrolled in a FIDE SNP, and our opposition pertains to auto-assignment of the new dual eligibles as well as the conversion of the current dual eligibles.

F. Transitioning Individuals into the Community Upon Reentry

The Arc of New Jersey would also encourage the State to consider extending some of the proposals in the Application currently targeted at former inmates or those with mental health or addiction issues, to individuals with I/DD. As stated in this section, by improving access to health coverage, recidivism can be reduced by reducing drug addiction, citing data published by the New Jersey Department of Corrections (DOC). The Waiver Application requests authority to allow formerly incarcerated people to retain Medicaid eligibility for 18 to 24 months before a redetermination. This is an excellent suggestion given the plethora of medical needs of re-entering offenders with mental illness and alcohol abuse issues, but we believe it would prove quite beneficial if also applied to former inmates with I/DD. We would also recommend extending the same retention of Medicaid eligibility to criminal offenders with I/DD who don't reach the state prison system and are therefore not counted in the DOC data. These individuals may be released from a county jail after serving a sentence there, being released upon a plea agreement of "time served," or having charges dismissed because of a lack of evidence or due to a determination of incompetency. These individuals are often clients of the Division of Developmental Disabilities.

An additional, serious obstacle to successful reintegration of people with I/DD is that SSI and Medicaid are both suspended after a 30 day county jail stay. Inmates must appear at the county board of social services to reinstate their benefits, which results in a gap upon release, during which released offenders have no access to money for housing, prescriptions or food and in the case of individuals who receive services from the DDD, they cannot access those services until Medicaid is back in place. Obtaining authority to expedite reinstatement and create a statewide, uniform system to address this need would reduce homelessness, psychiatric commitments and recidivism.

Furthermore, we recommend that the Department expand their plans regarding integrated behavioral health care homes for mental health and substance abuse populations to also include individuals with intellectual and developmental disabilities. Doing so would help reduce homelessness and recidivism.

Additional Comments and Recommendations

New Jersey Workability – Request for a DAC Exception

We highly recommend modifying the NJ WorkAbility Medicaid regulations to create a **"Disabled Adult Child (DAC) Exception"** for individuals with I/DD who are employed. When a parent of an individual with I/DD retires, becomes disabled, or passes away, the son/daughter receives a Social Security Disability Insurance (SSDI) benefit that is calculated on that parent's work record. In determining eligibility for NJ WorkAbility, whenever the SSDI income is

received due to the parent's work record, it is viewed as "unearned" income. However, whenever SSDI is received because of the person's own work record, it is viewed by NJ Medicaid as "earned" income, and it does not prevent the individual from being eligible for NJ WorkAbility. The current regulation has prevented some persons with I/DD who are otherwise eligible for NJ WorkAbility from receiving Medicaid. Furthermore, since the "baby boomers" are aging, many more parents will be retiring. Upon a parent's retirement (or disability or death), persons with I/DD who are currently receiving NJ WorkAbility will start to receive SSDI from the parent's work record, which would result in termination of their NJ WorkAbility Medicaid. Therefore, we urge that the NJ WorkAbility regulations are modified to develop a DAC Exception. This would allow the SSDI income received by a person with I/DD, which results from a parent's work record, to be viewed in the same way as SSDI income from the person's own work record.

Miller Trusts

We would also urge the Department to include the option of Miller Trusts for individuals with intellectual and developmental disabilities among the changes outlined in the Comprehensive Medicaid Waiver Application for Renewal. As you may know, Qualified Income Trusts, or Miller Trusts, are a recently added pathway for individuals, who have been assessed to need a nursing home level of care, to establish Medicaid eligibility when their monthly income exceeds the threshold of \$2,199. Although only currently available to the senior citizen population in New Jersey, we believe Miller Trusts could also serve as an additional resource for a small group of individuals with I/DD. It is our view that Miller Trusts will help persons with I/DD to protect their Medicaid eligibility and their access to DDD services. With this in mind, we believe the State should allow people with I/DD who have income that exceeds the \$2,199/month threshold (perhaps due to their current employment combined with a pension or Social Security Disability from a parent), who are receiving services from DDD, to create Miller Trusts. We ask the Department to add this to the Application.

Fast-Track System for the Community Care Waiver

We would also like to see the Department implement a "fast-track" system that would enable the re-enrollment of individuals who lose access to the Waiver because their source of Medicaid changes. For example, a 35-year-old woman with I/DD, who is on the CCW, is living in a group home. Both of her parents are employed. Suddenly, her father passes away, and the entire family is grief-stricken. The consumer starts to receive SSDI in the amount of \$1,500/month because of her deceased father's work record. Her SSI (and the Medicaid that accompanied it) and her CCW status are terminated. The mother would have to navigate the system, while still grieving, to have her daughter quickly returned to the CCW in order to maintain the very important group home placement. We are advocating for a fast-track process that would facilitate this individual returning to the CCW. A fast-track process would also be important for others with I/DD who

are confronted with the termination of the CCW because a parent has retired, become disabled, or passed away.

Rates in the Supports Program for the dually-diagnosed

Furthermore, we would like to express concern about the rates in the Supports Program as they relate to individuals who are dually-diagnosed, such as behavioral supports. We fear that the low rates for things like assessment/plan development and monitoring of behavioral plans, in combination with the high level of required credentialing, will result in network inadequacy and unavailable services for those we represent. As an example, the Children's System of Care within the Department of Children and Families requires less credentialing than the Supports Program for similar services, and it is still very difficult to find staff who are willing to work with youth who have extremely challenging behaviors. We fear that the Supports Program demands a lot of educational requirements for the person delivering the behavioral supports but does not also offer a reasonable rate to off-set this high bar. We ask that the Department address this matter in the Comprehensive Medicaid Waiver Renewal Application so that individuals who are dually-diagnosed will be able to receive the care they require.

Self-Advocacy

We also recommend that the State add Self-Advocacy among the approved services under the Comprehensive Medicaid Waiver. As New Jersey's service delivery model rapidly moves into a more self-directed driven system, Self-Advocacy will serve a critical role for people with intellectual and developmental disabilities. The new world, which will focus on budgets, community integration and increased choice, will require those served to speak up for themselves and voice their opinions about the services they receive and where and how they receive them. It is critical that served individuals be able to access the tools they need to learn how to advocate.

Legal Advocacy

In addition, we would like to see legal advocacy among the approved services under the Comprehensive Medicaid Waiver and we urge the State to include this in their proposal. There are times when people with I/DD experience a denial or reduction of a medical service. Specifically, this happens most often with Personal Care Assistance (PCA) services. Furthermore, individuals may run into medical procedure denials that require legal intervention in order to get them resolved, or there may be guardianship-related issues that necessitate a lawyer. For the reasons stated above, as well other legal issues that may impact people with I/DD, we believe there is a need to include legal services among the approved items in the Waiver.

Medicaid for those under the age of 18

We also encourage the State to include language in their proposal that would address individuals with I/DD under the age of 18 who require Medicaid, but they are not Medicaid eligible because

the family is not low income. This subsection of our population would likely be a small group, but it is one that often struggles mightily with severe and costly medical complications associated with their disability. Typically, these individuals are non-verbal and/or non-ambulatory and caring for them at home is a real challenge for family members. If these individuals were allowed to enroll in Medicaid, they would then have the coverage they need for personal care assistance and durable medical equipment, etc. We believe that while it may not be a huge number of people, those most impacted would benefit greatly from access to Medicaid. As soon as these individuals reach their 18th birthday, they can apply for SSI, and when the combined SSI and Medicaid benefit begins, they won't need Medicaid from the State any longer.

Data Collection

We want the Comprehensive Medicaid Waiver to mandate data collection and sharing of that data about the performance of the Managed Long Term Services and Supports (MLTSS) programs that serve individuals with I/DD and their families. In addition, we would like to see similar data collected and shared around the Supports Program. We believe advocates and stakeholders would benefit from data regarding how many individuals are served, what services they receive, the associated costs, etc. This will better equip the service delivery system to plan and advocate for the future.

Therapeutic Leave

In the new fee-for-service system, therapeutic and medical leave days will play an important role for both the served individual and the community provider agency delivering the services. In day habilitation programs, we believe individuals should be allowed 30 days of therapeutic leave with a 100% reimbursement to the community provider. Furthermore, individuals living in residential settings should also be allowed 30 days of therapeutic leave with a 100% reimbursement to providers. Similar to those without disabilities, served individuals should have the right to go on vacation, visit their families or stay with friends or significant others without worrying about losing their home. However in residential programs, we also recommend a 100% reimbursement to providers when an individual is absent from the home because of a hospital or rehabilitation stay. After a 30-day period, a reevaluation would take place to review the specific details of the person's situation and a plan for moving forward. This policy should be applicable in every medically-related absence and should include medical hospitalization, psychiatric hospitalization as well as rehabilitation stays. The State should also keep in mind that when an individual is in the hospital or a rehab facility, the provider very often continues to coordinate that individual's care and so in many cases he or she continues to receive service from the agency. Furthermore, while an individual is absent for medical reasons, providers are not able to reduce their costs by lowering staffing ratios because other residents of the home still require support.

We also want to note that providers have no way of controlling how long a person will be absent, but in many cases our population's disabilities lead to lengthier healing and rehabilitation periods. A group home is not just a placement; it is a person's home. With this in mind a person should not feel that their home is jeopardized because they required a stay at a hospital or a rehab center.

We also ask the State to consider the addition of a 100% reimbursement to providers, for 60 days, in the case of permanent vacancy. This will ensure providers have the necessary funds to serve other residents of a home while a new resident is identified and moved in. Realizing that it may take some time to find the new person and transition him or her, the 60 days may be extended if the provider is making reasonable efforts to fill the vacancy in a timely manner.

Respite

We ask the State to look at the current coding outlined for respite. The procedure code for the base respite service needs to be different than the procedure code for the out-of-home respite service.

Camp

The Arc of New Jersey believes steps must be taken to ensure individuals with I/DD can access summer camp services. Toward that end, it's important to explore what will work to provide appropriate funding levels for service providers. We recommend using the base respite rate to fund the day portion of summer camp programs. These programs provide invaluable benefit to those we represent and it's critical that proper funding is allotted to safeguard their continued availability.

Supports Brokerage

The Arc of New Jersey would also like to bring the State's attention to Supports Brokerage Service Limits. According to the Supports Program Manual:

"The service is only available to individuals who self-direct some or all of their services in their service plan and is intended to supplement but not duplicate the Support Coordination service. The extent of the assistance furnished to the participant or family is specified in the Service Plan. The Supports Brokerage services cannot be paid to New Jersey Provider agencies or employees of their agencies, legal guardians of the participant, or other individuals who reside with the participant."

In the Waiver Renewal Application, we recommend that New Jersey provider agencies be allowed to provide Supports Brokerage services. These agencies have the knowledge and capacity to provide this service and often have long histories of advocating for and with the individual. We don't believe there is a conflict of interest because the Supports Broker is not

duplicating the service coordinator and the service coordinator is the entity working with the individual to select a provider. Furthermore, there is no conflict of interest because the types of services delivered by the Supports Broker are not related to the services delivered by a service provider. Since by definition Supports Brokers work with individuals who are self-directing, they would not be receiving agency-directed services for the area the Supports Broker is providing assistance. For example, Section 17.21.4 of the Supports Program Manual provides a list of examples, all of which are related to the individual hiring their own worker, which is outside the realm of the service provider.

In addition, we believe guardians who do not reside with the participant should be allowed to provide Supports Brokerage services. Managing workers is a time consuming responsibility. Corporate Guardians cannot take this on without compensation for the extensive time spent, yet individuals do not have enough funds from Social Security to pay fees to compensate Corporate Guardians for these duties. Thus, even if self-direction is the best option for the individual they can't have their services provided this way because their guardian cannot assume these extra duties without compensation. Similarly, family members who do not live with the individual and who are also guardians cannot take on this burden without compensation. Therefore, individuals who could succeed in a self-directed environment have to choose agency-provided services. We believe that if the Guardian could provide the service, it would open up opportunities for more individuals to participate in self-direction.

Closing

We thank the Department for the opportunity to weigh in on this tremendously important Wavier Renewal and we look forward to continued conversation and discussion as the process continues.

Sincerely,



Thomas Baffuto
Executive Director