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**NJ Legislative Disability Caucus  
Access to Healthcare for Individuals with  
Intellectual and Developmental Disabilities (IDD)  
April 26, 2022**

Good afternoon.

Thank you to the co-chairs and all of the legislators on this call for focusing on this important issue, and for your commitment to people with intellectual and developmental disabilities.

The Arc of New Jersey is the State's leading advocacy and service organization for children and adults with intellectual and developmental disabilities and their families.

My name is Beverly Roberts. I am the Director of The Arc of New Jersey's Mainstreaming Medical Care Program, and I have had this position for more than 30 years.

I agree with all of the concerns about low Medicaid rates that Assemblyman Greenwald discussed a few minutes ago.

**In addition to those concerns, I will discuss two overarching problems pertaining to Medicaid that individuals with intellectual and developmental disabilities (IDD) are encountering:**

1. The lack of specialty programs to serve the medical and dental care needs of individuals with IDD, particularly those who have complex disabling conditions, and
2. The lack of behavioral health and psychiatric services for individuals who are diagnosed with both IDD and co-occurring behavioral or mental health challenges.

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Before I provide information that is specific to these important health care issues, I would like to take a moment to explain the wide scope of health care needs and challenges among some individuals with IDD.

You may know that the term “IDD” encompasses a number of different diagnoses and includes the following: intellectual or cognitive disabilities; autism; cerebral palsy; epilepsy; and spina bifida, as well as some other conditions. Furthermore, some individuals have multiple disabling conditions, for example, having an intellectual disability and autism and also a seizure disorder.

Within each type of disabling condition, many individuals have a “mild” disability, while others have a disability that is more significant. When a person with IDD has a disabling condition that is more severe, it is more likely that there will be additional associated difficulties such as being non-verbal or having very limited ability to communicate. Some of these individuals may also have very complex medical conditions, requiring diagnosis and treatment from physicians who have specialized training and experience. For example, some individuals have difficult-to-control seizures; some individuals have gastrointestinal issues, which may range from having chronic constipation to aspirating when eating, to requiring a G-tube because of significant feeding and swallowing problems. It is more likely that some individuals with more severe IDD may also have significant behavioral challenges.

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**There is some good news and some bad news** about health care for individuals with IDD who have disabling conditions that require more time and more expertise from the treatment team to provide appropriate diagnosis and treatment.

**The good news** is that there is a type of care that works very well to diagnose and treat individuals with IDD who have complex healthcare problems. I'm referring to specialized programs with staff who are trained and experienced in caring for the health and mental health needs of these individuals. Specialized programs have a team of healthcare professionals who provide comprehensive, patient-centered and coordinated care to individuals with IDD. These healthcare programs are affiliated with some of the Medicaid MCOs, but they also have additional funding to cover the costs associated with their very specialized services.

**Now for the bad news:**

**Unfortunately, there are very few such specialized health care programs for individuals with IDD in New Jersey, and we need more of them!** One such program is the Rowan Integrated Special Needs Center – RISN – located in Sewell, in Gloucester County. There is another specialized healthcare program in north Jersey, which is affiliated with Morristown Medical Center and Overlook Medical Center's Union Campus. However, these healthcare programs are **not** sufficient to meet the needs of the many individuals with IDD across New Jersey who need specialized health care.

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**The next major area that I want to address is the need for appropriate diagnosis and treatment for individuals with IDD who have co-occurring mental health challenges.**

Although the exact prevalence of co-occurring mental health challenges for individuals with IDD is unknown, the National Association for the Dually Diagnosed (NADD) estimates that approximately 35% of people with IDD also have mental health challenges.

Individuals *with* IDD can have the same types of mental health issues that occur in persons *without* IDD, including bipolar disorder, schizophrenia, depression, anxiety, obsessive-compulsive disorder or substance abuse. Furthermore, some individuals with IDD who have severe challenging behaviors, may also have *additional* serious behavioral problems such as self-injury, head-banging, and aggression. There has also been a significant impact due to COVID, including loved ones of individuals with IDD who passed away from COVID. Sadly, many individuals with IDD have not had access to appropriate grief counseling.

**There are two major problems for Medicaid enrollees with IDD who need to access mental health care in New Jersey:**

**The first problem** is that individuals with IDD and co-occurring mental health challenges often need to see mental health professionals who have had *specialized training and experience* in providing accurate diagnosis and treatment. Although there is a significant

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scarcity of mental health professionals for the general population, the need is also very urgent for individuals with IDD who are dually diagnosed.

**The second problem** is that in New Jersey everyone with this type of dual diagnosis, who has Medicaid-only and receives DDD services, **must** receive mental health care from providers who are in the network of their Medicaid managed care organization. Problems can arise when an urgently needed medical specialist and a specialized mental health provider are not in the same Medicaid MCO.

There are only a small number of programs in NJ where Medicaid enrollees with IDD who are dually diagnosed can access specialized mental health care. However, the currently available specialized mental health care is not nearly enough to meet the urgent need, and some locations have a lengthy waiting period for new patients.

In our shared goal of improving access to appropriate health and mental health care for Medicaid beneficiaries with IDD who have complex problems – some of whom may be nonverbal or minimally verbal, and not able to describe how they are feeling -- it is essential that additional, specialized medical, dental, and mental healthcare programs be developed. In conclusion, these specialized programs must be included in the Medicaid MCO networks, and must be staffed by health care providers with the appropriate training and experience – and the staff must receive a salary commensurate with their level of expertise.

Thank you.