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Statewide Parent Advocacy Network, Inc.

Family Voices comments on the CMS Interim Final Rule for Medicaid Optional State Plan Case Management Services

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We are writing on behalf of Family Voices NJ concerning the CMS Interim Final Rule for the Medicaid Optional State Plan Case Management Services. Family Voices is a national network that advocates on behalf of children with special healthcare needs and our NJ Chapter is housed at the Statewide Parent Advocacy Network, NJ's federally funded Parent Training and Information Center. The Family Voices Coordinator also serves as the NJ Caregiver Community Action Network representative for National Family Caregivers Association in a volunteer capacity. NFCA represents parents of special children, "well-spouses", and those involved in eldercare. In addition, SPAN is the Family-to-Family Health Information Center for the state, and a chapter of the Federation of Families for Children's Mental Health. It is from the perspectives of the many families we assist and our experiences as caregivers, that we are sharing these comments.

Overall, we are concerned with the effect this will have on those with developmental disabilities and mental health issues, as they require complex care across multiple systems. We see this as restricting their access to medically necessary services. Even the stipulation that "states may target case management services by age, type or degree of disability, illness or condition..." is limiting in that even within the same diagnosis, there is a range of abilities. For example, people with a developmental disability such as cognitive impairment have various levels of functioning. The same holds true for a developmental disability on the autism spectrum ranging from mild Asperger Syndrome to classic, nonverbal autism. Further complicating matters are if there are comorbidities, particularly in cases of dual diagnosis of a developmental disability *and* mental health issues (there are currently 4000 children in NJ).

In general, CMS states that case management will allow "access to needed medical, social, educational, and other services". Yet children can have multiple case or care managers depending upon the system in which they are served. For example, a

Medicaid eligible child with a dual diagnosis of developmental disability and mental health issues in the foster care system would have the following:

- Division of Youth and Family Services (child protective services) case manager
- Medicaid HMO care manager for special needs
- Special Child Health Services (Title V) case manager for special needs
- Child Study Team case manager for education
- private school case manager for out-of-district placement
- children's hospital social worker
- transition coordinator for the Division of Vocational & Rehabilitation Services
- Child Behavioral Health Services youth case management for mental health
- Division of Developmental Disabilities case manager
- there may also be involvement in the juvenile justice system

We support the notion that “child protective services are the direct services of State activities of child welfare programs and are not Medicaid case management”. We also agree that “while some of the services identified on a child’s IEP (e.g. a related service such as physical therapy) may be covered under Medicaid, the development, review, and implementation of the IEP is part of the process that is required by Part B of the IDEA...This process should not be confused with Medicaid case management.” In addition, we also support the exemption from case management for public guardianship programs. However, although we agree that “recipients have free choice of qualified providers”, we disagree that this will “reduce the likelihood of service duplication”. Each system has its own area of expertise. A case manager dealing with a physical condition such as HIV-AIDs or Down Syndrome and resulting cardiac complications for example, may not have knowledge of mental health issues and vice versa. In our state, there is a lack of services for children with a dual diagnosis of developmental disability and mental health issues. The DD community doesn’t know how to handle mental health issues as they base treatment on behavioral modification techniques such as Applied Behavioral Analysis used by behaviorists. The mental health community doesn’t know how to deal with the challenging behaviors caused by the developmental disability and representatives from our children’s mental health system actually stated at meetings that “children with developmental disabilities are incapable of benefiting from mental health treatment”. If a child with a developmental disability says, “I’m going to kill you” or “I’m going to kill myself”, they don’t need a behaviorist, they need mental health treatment. Indeed, we recently reviewed grant proposals for a state RFP on treatment for children with DD/MH issues and only one provider had experience with the DD population. If these two systems, the very two that CMS is using for targeted case management, can’t collaborate, how will this improve access to healthcare? In a case involving multiple systems, this becomes even more complex. We do not see how it is possible to implement the concept that “case management services must be provided by a single Medicaid case management provider”. Further, we disagree “when an individual has both mental retardation and a mental illness...a decision must be made concerning the appropriate target group so that the individual will have one case management provider” for the reasons stated above. We participate on national conference calls with both the National Alliance for the Mentally Ill as well as Georgetown University National Technical Assistance Center for Children’s Mental

Health and are hearing that there is a lack of services for children with a dual diagnosis of a developmental disability and mental health issues nationwide.

We do agree that case management should be on a “fee-for-service, as opposed to a capitated basis” to avoid the “head count” mindset. However, there is nothing stipulating the frequency/amount/duration of case management services, which is deeply concerning. In NJ, the Medicaid HMOs consider the DD population to be the most stable and their care management for special needs consists of a single phone call per year. So if the Medicaid HMO care manager, for example, is chosen as “the single Medicaid case management provider”, this means this population will only receive case management once annually for all of their “medical, social, educational, and other services” needs. We are also deeply concerned regarding the statement that “the most efficient and economical unit of service is a unit of 15 minutes *or less*”. The populations for targeted case management, namely developmental disabilities and mental health, have difficulty communicating due to the very nature of their disabilities, and require extra time during medical visits. We are concerned that that “15 minutes” will be seen as the minimum standard and strongly disagree that all “medical, social, educational, and other services” needs can be addressed with a person who has either a developmental disability and/or mental health issue within this timeframe.

Although we agree that foster care, certain educational services, and public guardianship should be exempt as Medicaid case management, we think there needs to be further clarification and collaboration regarding other services in multiple complex systems for individuals with developmental disabilities and mental health issues, and we disagree with the notion of a single Medicaid case management provider. Thank you for the opportunity to comment on the CMS Interim Final Rule for the Medicaid Optional State Plan Case Management Services and considering our concerns for this vulnerable population.

Sincerely,

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Our Mission: To empower families and inform and involve professionals and other individuals interested in the healthy development and educational rights of children, to enable all children to become fully participating and contributing members of our communities and society.