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Patricia Johnston

February 16, 2018

The Honorable Orrin G. Hatch, Chairman
The Honorable Ron Wyden, Ranking Member
U.S. Senate Committee on Finance
Washington, DC 20510

Dear Chairman Hatch and Ranking Member Wyden:

The National Association for Children's Behavioral Health (NACBH) appreciates the opportunity to respond to your February 2, 2018 request for information and recommendations to improve Medicare's and Medicaid's response to the opioid epidemic.

NACBH represents multi-service treatment and social service agencies providing a wide array of behavioral health and related services to children, youth and families. Services provided by NACBH members include assessment, crisis intervention, psychiatric hospitalization and partial hospitalization, residential treatment, group homes, therapeutic foster care, independent living, in-home treatment, respite, outpatient counseling, special education services, and a wide range of community programs and outreach. Medicaid pays for the majority of behavioral health services delivered by our members, who are also connected with child welfare, juvenile justice, and educational systems in their communities.

There is an overarching access barrier to appropriate mental health and substance use disorder treatment in Medicaid: the Institutions for Mental Diseases (IMD) exclusion. There have been more than a few proposals and discussions around eliminating it in order to provide access to residential treatment for non-elderly adults with substance use disorders. But there is another, growing population affected by both the opioid epidemic and the IMD exclusion – children and youth, particularly those in out-of-home foster care placements.

Attached are brief descriptions of how the IMD exclusion adversely affects Medicaid-enrolled children, and a crucial misalignment with the federal IV-E foster care program. Congress has just made that misalignment worse by passing the Family First Prevention Services Act (FFPSA) as part of the Bipartisan Budget Act. The FFPSA raises the urgency of eliminating the IMD exclusion in two ways:

- It creates Qualified Residential Treatment Programs (QRTPs) as one of several congregate alternatives to family-based foster homes, to serve the behavioral and emotional needs of foster children that cannot be met in a community setting. A QRTP with more than 16 beds would meet the definition of an excluded IMD (not one of the three allowable types of IMDs for enrollees under age 21), meaning that the state could not legally claim Medicaid FFP for any health care services provided to its residents.

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- It provides foster care maintenance payments for children with parents in a licensed residential family-based treatment facility for substance abuse. Again, if the facility has more than 16 beds, it fits the definition of an excluded IMD, and no federal Medicaid matching payments could be legally claimed for any of the health services received by its residents.

NACBH has repeatedly raised these issues with Congress, most recently with the Committee when the FFPSA was being drafted and refined. They were not addressed. The law is silent on the payment source for health care services for children in QRTPs and family-based residential treatment facilities. As HHS develops regulations to implement the FFPSA, and states subsequently reform their child welfare licensing and reimbursement systems, it is imperative that Congress resolve the underlying conflict with the Medicaid statute.

The time has come to eliminate the IMD exclusion, rely on clinical and psychosocial assessments to identify appropriate living and treatment environments, and end the wasteful work-around for every adjacent policy. Implementing parity in Medicaid? Updating the managed care regulations? Serving the health care needs of children in foster care? Addressing the opioid epidemic? The common obstacle to the most sensible approaches is the IMD exclusion.

We also recommend that the Committee convene a work group with CMS and ACF to fully inform the rulemaking process for the FFPSA, and identify any needed legislative fixes. With Committee jurisdiction over both Medicaid and child welfare, you are in a singular position to ensure that the programs work seamlessly together to serve our most vulnerable children and youth.

We appreciate your consideration of our comments.

Sincerely,



Patricia Johnston
Executive Director

UNDERSTANDING THE MEDICAID IMD EXCLUSION'S EFFECT ON CHILDREN

As the larger healthcare system is implementing new models of care and coordination, developing the evidence and practice base for more effective treatment services and delivery systems, children's providers are asked to deliver 21st century results within an antiquated Medicaid construct.

The Medicaid IMD exclusion is a significant barrier to delivering the right treatment at the right time for the right duration – the most cost-effective approach to positive health outcomes – to children and youth with mental and substance use disorders. With an estimated 40% of American children covered by Medicaid, the time has come to bring the law up to date with practice.

WHAT IS THE IMD EXCLUSION?

When the Medicaid program was established in 1965, it specifically excluded federal financial participation (FFP) for any health care services provided to enrollees under age 65 residing in Institutions for Mental Diseases (IMDs). IMDs were defined as institutions primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases. "Mental diseases" are the mental and substance use disorder diagnoses in the Diagnostic and Statistical Manual of Mental Disorders (DSM).

In 1988, the definition was narrowed to only "facilities" with more than 16 beds. However, in some circumstances, beds are counted cumulatively across multiple facilities owned by the same entity, even when they are separately licensed and when the licensing categories vary. The law does not exclude any licensing category from the definition, e.g., a nursing home, group home, child caring institution, or other facility can be identified as an IMD.

In 1972, a limited exception to the IMD exclusion was established for individuals under age 21, known as the Psych Under-21 benefit. It allows only three types of IMDs to receive federal Medicaid reimbursement for enrollees under age 21: psychiatric hospitals, psychiatric units of general hospitals, and Psychiatric Residential Treatment Facilities (PRTFs), each specifically defined in Medicaid regulations. Not all residential treatment centers are PRTFs, and not all states have PRTFs – only about half do.

HOW THE IMD EXCLUSION LIMITS APPROPRIATE AND NECESSARY SERVICES

There is a widespread misperception that the Psych Under-21 benefit allows children to receive necessary services in a wide variety of settings. It does not. For the overwhelming majority of 24-hour settings that meet the definition of IMDs, states may not legally claim FFP for any of the health care services provided to children residing in them, whether mental or physical, and whether provided on- or off-site.

Under the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, Medicaid is obligated to pay for all medically necessary Medicaid services for eligible enrollees under age 21 – but not if a child resides in an excluded IMD. This is true for all Medicaid-enrolled children, whether in their parents' custody or in out-of-home foster care placements.

The very narrow Psych Under-21 benefit was a first step towards increasing access to mental health services for children and adolescents. However, it only authorized FFP for the inpatient psychiatric services, not the full range of services available under EPSDT. In November 2012, new federal guidance gave states the option of including physical health services in active plans of care, and therefore FFP, for children receiving Psych Under-21 services. The 21st Century Cures Act passed in December 2016 went a step further by requiring EPSDT coverage for children in allowable IMDs, effective January 2019. While welcome, it will provide only incremental relief from the larger discriminatory barrier imposed by the IMD exclusion.

Addressing the Mental Health of Youth in Foster Care

Principles

- Individualized needs must drive case planning and treatment planning, with the involvement of the child and family.
- Placement and treatment decisions must be based on comprehensive physical, mental, developmental, functional and environmental assessments.
- Services must support children and families in their homes and communities, whenever indicated by comprehensive assessment.
- A full array of treatment and support services must be available to meet the complex needs of children and families experiencing mental or emotional disturbance or other traumatic events.
- Services must be coordinated across child-serving systems.
- The scope and duration of treatment and support services must be determined by ongoing assessment and measurement against outcome goals.

Background

Most children and youth served by child welfare agencies are also eligible for Medicaid. Child welfare is responsible for their safety, wellbeing and permanency, and Medicaid is responsible for their health care. Both programs are federal-state partnerships, and each has evolved over time in terms of both federal requirements and state options to best meet their population's needs. However, what should be a collaborative, comprehensive approach to improving the functioning and future prospects of these children is not. The federal child welfare and Medicaid laws disconnect where they should most logically meet, if not overlap: mental health. And the gap widens with every discussion of reforming either program without considering how both should work together for children and families.

Mental Health Gaps Between Child Welfare and Medicaid

States receive federal financial participation under Title XIX Medicaid (for health care and treatment services) for virtually all children in foster care, and Title IV-E foster care assistance (for room, board and maintenance) for about 40 percent of them. States rely on these federal funding streams to substantially underwrite the costs of caring for children and youth in their custody. However, differing requirements and practices of the two programs create a significant gap in a critical area: mental health.

It is well documented that foster children and youth have much higher mental health needs than their non-foster care peers. Studies have demonstrated that rates of mental illness are high among children who have experienced maltreatment and have been in foster care. Many children meet diagnostic criteria for major disorders before entering foster care, indicating that it is frequently the experience of maltreatment, not foster care, that predicates mental health problems (McMillan, et al, 2005). By the time they are teenagers, 63 percent of children in foster care have at least one mental health diagnosis; 23 percent have

three or more (White, Havalchack, Jackson, O'Brien & Pecora, 2007). According to a 2010 study of Medicaid-enrolled children in thirteen states, children in foster care were prescribed antipsychotic medications at nearly nine times the rate of children enrolled in Medicaid who were not in foster care. The alarming over-prescription of powerful psychotropic drugs, which have not been tested for safety and effectiveness in children, points to a clear lack of assessment, monitoring and referral to appropriate services.

A common misconception about Medicaid is that under the Early and Periodic Screening, Diagnosis and Treatment mandate (EPSDT), states provide all medically necessary Medicaid services to enrolled children and youth, including a comprehensive array of mental health services. While it is true that Medicaid covers an increasingly robust variety of outpatient, in-home, peer support and other community-based mental health services, there are too few options for beneficiaries who need a 24-hour treatment environment that falls below an acute care setting.

When Medicaid was established in 1965, it included an IMD exclusion stating that federal financial participation is not available for any services provided to an individual who is under age 65 and is a patient in an institution for mental diseases (IMD). The intent was to prevent states from shifting costs which historically they had borne to the federal government. In 1972, the law was changed to establish an exception to the IMD exclusion for individuals under age 21 through a benefit called Inpatient Psychiatric Services for Individuals Under Age 21, commonly referred to as the "Psych Under-21" benefit. It allows inpatient psychiatric services in three settings: psychiatric hospitals, psychiatric units in general hospitals, and other settings as defined by the Secretary. Thus far the Secretary has defined only Psychiatric Residential Treatment Facilities (PRTFs) as an "other setting," and only about half the states license and regulate them.

When the under-21 exception to the IMD exclusion was established, Medicaid covered children's mental health services based on a traditional medical model of care: outpatient and inpatient. Many treatment models and settings have been developed in the four decades since then to better serve individual needs and respond to changing community standards on where and how services should be delivered, but the Medicaid program has not been updated to include them. A strict interpretation of the IMD definition – institutions of more than 16 beds that are primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases – inhibits provider agencies from developing a robust array of services if their cumulative bed count would exceed 16. This, in turn, prevents administrative economies of scale, seamless service delivery for children who move between levels of care and, ultimately, the availability of necessary and effective services that should be provided under EPSDT.

The conflict for states is that ensuring the safety of foster children with significant behavioral health needs can mean placement in 24-hour settings which meet the definition of an IMD but are not one of the three allowed within the Psych Under-21 benefit. Legally, Medicaid should not be paying their health care claims. However, the Centers for Medicare and Medicaid Services relies on states to comply with the exclusion, including identifying which facilities are IMDs. This has led to various levels of interpretation and compliance across the country, and confusion about whether compliance is even necessary. The IMD exclusion is antiquated and not uniformly applied. Eliminating it would remove a legislative barrier to necessary services, effective clinical practices and cost efficiencies.¹

¹ A more comprehensive review of the IMD exclusion is available online at www.nacbh.org, under "About Us," *Rationale for Eliminating the IMD Exclusion for Medicaid Beneficiaries Under Age 21*.

Assessment

Jane Knitzer's 1982 ground-breaking report, *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services*, was the first significant study to identify the service gaps for children most in need. She found that many children were inappropriately receiving services at more restrictive levels of care than were needed, due to lack of alternative resources. The 1999 Supreme Court *Olmstead* decision energized the trend, started in the 1960s with de-institutionalization, to transform the delivery system and transition individuals from institutions to community services and settings in compliance with the Americans with Disabilities Act. In this decision, the Supreme Court ruled that states must have a "comprehensive, working plan for moving qualified individuals in institutional settings to less restrictive settings." The Surgeon General's 1999 *Report on Children's Mental Health* and the United Nations Convention on the Rights of the Child emphasized that treatment should be considered a basic right for families that suffer from a mental health or substance use disorder. In 2001, the President's New Freedom Initiative, designed to encourage the development of community-based services, stated that there should be "no wrong door" for accessing services.

Assuring that the right services are accessed must begin with a comprehensive assessment of a child's physical, mental, developmental, functional and environmental status, continuing with reassessment at specific intervals. The assessment must be at the core of an individualized service plan to meet the unique needs of each child and family. Tools exist, such as the Early Childhood Service Intensity Instrument (ECSII, for ages 0-5 years) and the Child and Adolescent Service Intensity Instrument (CASII, for ages 6-18 years), which link comprehensive assessment to the appropriate level of care and service intensity, taking into account relevant dimensions of safety, function, and family and environmental resources. We must continue to develop multi-dimensional assessment tools to identify problems as early as possible to ensure that children and families receive timely and adequate services, monitor outcomes, and inform development of responsive programs.

Unfortunately, child welfare position papers and legislation currently floating on Capitol Hill reject a common sense approach of using assessment to determine the right services at the right time in the right amount. Under the banner of reinvestment, they would prohibit or strictly limit federal financial participation for some settings, based solely on their congregate or group nature, and unrelated to a child's individual needs or circumstances. If these funding restrictions are adopted, there is tremendous potential that mental health services and supports will become even less accessible and responsive to the children who need them most.

Any reform of the child welfare system must examine Medicaid's role in providing health care, as well as what states will be required to fully finance if federal reimbursement is further restricted under Titles IV-E and XIX.

Common Language

Contributing to the misalignments of child-serving systems is a lack of common language. Terminology can be based in federal law, state licensing, academic theory, front-line practice or philosophical values. Language that is outdated or ambiguous, in particular, invites unintended consequences. For example, "institutions," "congregate care," "group placements" and "residential care" have been used almost interchangeably to refer to an array of 24-hour settings developed to respond to different treatment and safety needs. The antiquated and imprecise usage reveals, at best, a lack of understanding of current evidence-informed practice and, at worst, a desire to invalidate a group of services or providers.

A prerequisite to system reform must be the development of consistent terms to define child welfare and mental health placements and services.

Recommendations

- Do not reduce or eliminate federal financial participation for existing placement and treatment options until capacity is established in other settings or services that are more responsive to assessed need.
- Develop common terminology defining child welfare and mental health placements, settings and services, including the purpose, attributes, eligibility and payer for each.
- Direct relevant agencies within the U.S. Department of Health and Human Services to develop a 5- to 10-year child welfare-mental health workforce development plan, engaging professional schools, clinical guilds, provider agencies, family and foster family organizations in the effort.
- Eliminate the Medicaid IMD exclusion for enrollees under age 21.
- Fully implement EPSDT, ensuring state accountability and federal oversight.