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Delivery of Specialty Mental Health Services for Youth Without Documentation of Diagnosis

Statement of Need

California's mental health system has long assumed that decisions about a youth's treatment must be based upon a mental health diagnosis. This assumption, however, often blocks access to much needed care. The need to wait until a child's symptoms have deteriorated to the point that a diagnosis is warranted has delayed access to critical early interventions. In addition, in the case of youth who do meet the criteria for a diagnosis, the diagnostic label itself can often do more harm than good. For some young people, for example, a diagnosis can rupture a therapeutic relationship (which we detail with examples in this paper); sabotage a youth's future employment prospects; or pathologize behaviors that are better understood as consequences of poverty and/or structural racism.

New state reforms adopt a more comprehensive approach to eligibility for services that looks beyond the question of whether a youth meets the criteria for a mental health diagnosis and considers instead the full constellation of factors that shape a young person's mental well-being. Recognizing that Adverse Childhood Experiences (ACEs) can severely jeopardize a child's long-term physical and mental health, CalAIM's Specialty Mental Health Services (SMHS) Access Criteria create access to necessary SMHS for youth who have experienced child welfare or juvenile justice involvement; are experiencing homelessness; or who receive a high-risk score on a trauma screen tool – regardless of whether the

youth has received a mental health diagnosis.¹ Medi-Cal Managed Care Plans (MCPs) similarly must provide clinically appropriate care to youth who may not yet have a diagnosis but who face any of a wide range of risk factors, such as food insecurity, severe and persistent bullying, or a parent struggling with substance use issues.²

To support this more holistic approach to eligibility, recent DHCS guidance has highlighted the value of “Z-Codes” that document many Social Determinants of Health (SDOH).³ Z-Codes can both: 1) meet the federal requirement for an ICD-10 claiming code and 2) support a shared language that describes traumatic experiences and other SDOH. Because Z codes typically describe risk factors rather than formal mental health diagnoses, this paper does not include Z codes in the term “diagnoses.”

Despite these reforms, many administrators remain narrowly focused on mental health diagnoses as the primary driver of individual treatment decisions. Some Mental Health Plan (MHP) leaders, for example, have stated that youth may not continue to receive SMHS if they have not received a mental health diagnosis by the end of the assessment period. If a youth does not meet the criteria for a diagnosis, they reason, the youth should either stop treatment or transfer to an MCP for less intensive services. In addition, some county leaders have stated that, if a youth does meet the criteria for a mental health diagnosis, their clinician must document that diagnosis, even if they have determined the diagnosis could be harmful to the youth.

Proposal

Seneca Family of Agencies and the California Alliance of Child and Family Services would recommend that, in the case of youth who meet one of the SMHS Access Criteria, DHCS instruct counties to cover all necessary SMHS -- without the requirement for a diagnosis – for both: 1) youth who would not meet the criteria for a diagnosis and 2) youth who might be harmed by a diagnostic label. More specifically, we ask that DHCS implement the two recommendations outlined below.

- 1. Clarify that youth who meet SMHS Access Criteria are eligible for all SMHS – for as long as those services are medically necessary – regardless of whether the youth has received a diagnosis.**

We urge DHCS to confirm that, for youth who meet one of the SMHS Access Criteria, eligibility for SMHS is based not on the presence of a diagnosis, but instead on whether the services are medically necessary. We understand that some MHP leaders may be reluctant to serve a youth without a diagnosis because counties historically have relied upon diagnoses to help demonstrate that a youth requires the intensity of services provided by the MHP. Medical necessity for SMHS, however, can be established without a diagnosis, by describing instead the individual symptoms, needs, and risks that will be alleviated by the SMHS. Clinicians can rely, for example, on the required Child and Adolescent Needs and Strengths (CANS) tool, which guides clinicians in documenting the specific needs to be addressed. Listed below are hypothetical examples of youth for whom SMHS would be medically necessary, even though the youth do not meet the criteria for a mental health diagnosis.

¹ [Behavioral Health Information Notice 21-073](#).

² [Non-Specialty Mental Health Services: Psychiatric and Psychological Services](#), p. 18.

³ [All Plan Letter 21-009](#), revised February 3, 2022.

- The child requires a type of service that is not offered by the MCP.

Shantel is a two-year-old foster youth who suffers from debilitating separation anxiety at day care, where she becomes withdrawn and experiences frequent meltdowns. In part due to her young age, she does not meet all of the criteria for a diagnosis of anxiety. Her foster caregiver is at risk of losing her job because, due to the toddler's frequent tantrums, the childcare center repeatedly has asked her to pick up the child in the middle of the day. A clinician has determined that the child requires both therapy and frequent individual rehabilitation services at the day care center to help her practice the skills she needs to manage her anxiety and engage in activities at the childcare center. The MCP, however, offers neither rehabilitation services nor services delivered in the community. As a result, community-based rehabilitation SMHS are medically necessary for Shantel.

- The youth requires services provided with greater frequency and/or intensity than the services offered by the MCP in their county.

In his previous foster home placement, six-year-old Mark experienced sexual abuse and neglect. He now is attempting to process and assign meaning to those experiences, which has caused him to re-enact some of the sexual abuse he endured. Based on his experiences of abuse and disruptions in caregiving and attachment, the clinician has considered a diagnosis of Post-Traumatic Stress Disorder (PTSD). While the child has directly experienced trauma, however, he is not displaying other required symptoms for that diagnosis, such as avoidance symptoms or alterations in arousal and reactivity associated with the event. On the other hand, he is displaying behaviors that are very concerning, such as attempting to sexually touch his siblings. Therefore, although he does not meet the criteria for a formal mental health diagnosis, he does require intensive services to help him learn how to better manage his emotions and reduce his inappropriate behaviors.

The therapist has determined that Mark is likely to require therapy at least twice weekly for a sustained period of time. Mark also requires extensive case management services, including frequent in person participation in his Child and Family Team (CFT) meetings and in his Individualized Education Program meetings, to ensure that he is receiving adequate supports at school. Although the MCP may offer Enhanced Care Management (ECM) services for child-welfare involved youth in the future, the anticipated monthly payments for these services will not be sufficient to cover the intensity of case management services that Mark requires. Because the MCP does not offer therapy and case management at sufficient levels of intensity, he should receive those services from the MHP.

- The services offered by the MCP are not accessible for the youth.

Dawn is a 4th grader who recently witnessed an incident of community violence. Soon after this event, she began struggling with insomnia and nightmares. An MHP therapist who works at Dawn's school has administered the PEARLS and discovered that Dawn scored a 4, indicating that she is at high risk of developing a future mental health disorder. The therapist has determined that Dawn does not meet the criteria for a diagnosis of anxiety, in part because her symptoms have emerged only recently. Her therapist nevertheless has concluded that, particularly in light of her previous traumatic experiences, Dawn urgently requires therapy to address her insomnia and nightmares.

The MCP in which Dawn is enrolled only offers therapy through an office-based provider during normal office hours. Dawn lives with her mother, who works full time and is not able to drive Dawn to the clinic

for these services. In this situation, although Dawn does not have a mental health diagnosis and needs only a type of service that is offered by her MCP, she nevertheless should qualify for SMHS from the MHP-contracted therapist working at her school because the MCP does not offer services that Dawn can access.

Of course, as CalAIM and the Children and Youth Behavioral Health Initiative reforms lead more MCPs to offer services in schools and other community-based locations, many youth may find that their MCP services are equally or more accessible than those offered by the MHP. In these situations, the youth could be referred to the MCP.

2. In the case of youth who do meet the criteria for a diagnosis, clarify that providers may decide whether or not to document that diagnosis, depending on whether the diagnosis would support or hinder the youth's treatment.

Some county leaders have stated that, if a youth does meet the criteria for a diagnosis, the provider must document that diagnosis. They reason that a diagnosis is essential to treatment planning for every individual. Yet, with the new SMHS Access Criteria, providers will need to develop treatment plans for many youth who do not have a diagnosis. As noted above, care plans for these youth will instead be based on actionable items identified in their CANS assessment, as well as any additional factors identified by the clinician. We ask that DHCS give providers the same flexibility in the case of youth for whom a diagnosis could prove counterproductive.

Although clinicians seek to work collaboratively with youth and their family members to develop a diagnosis, there are nevertheless several types of situations in which the youth could be better served without a diagnosis. Researchers have documented, for example, the stigma attached to many types of mental health diagnoses, including Attention Deficit Hyperactivity Disorder (ADHD),⁴ depression,⁵ and Post Traumatic Stress Disorder (PTSD).⁶ Because of these perceptions, there are many young people and caregivers who do want help addressing the specific challenges they face but who would feel alienated and/or betrayed if their therapist described those challenges as a mental health disorder. If given a diagnosis, many of these youth, and/or their family members, will resist or withdraw from treatment.

The stigma associated with some disorders, such as Oppositional Defiant Disorder (ODD) and Conduct Disorder, can be especially harmful. Experts warn, for example, that youth diagnosed with ODD can enter a harmful cycle in which they experience both decreased self-esteem and lowered expectations from authority figures, which can lead to more disruptive behaviors.⁷

Youth from disproportionately affected communities also face a higher risk of inaccurate diagnoses. A study of youth in a long-term juvenile justice facility, for example, found that, after controlling for

⁴ Mueller, A.K., et. al. (2012), Stigma in Attention Deficit Hyperactivity Disorder, *ADHD Attention Deficit and Hyperactivity Disorders*, 4, 101-114.

⁵ Yokoya, S. et. al. (2018), A Brief Survey of Public Knowledge and Stigma Towards Depression, *Journal of Clinical Medicine Research*, 10(3): 202-209.

⁶ Krzemieniecki, A., and Gabriel, K. (2021), Stigmatization of Posttraumatic Stress Disorder is Altered by PTSD Knowledge and the Precipitating Trauma of the Sufferer, *Journal of Mental Health*, 30(4): 447-453.

⁷ Beltran, S. et. al. (2021), A Call to Revise the Diagnosis of Oppositional Defiant Disorder—Diagnoses Are for Helping, Not Harming, *Journal of the American Medical Association Psychiatry*, 78(11).

adverse childhood experiences, criminal offending, juvenile justice placement history, and individual risk factors, Black males were 40% more likely than White males to be diagnosed with Conduct Disorder.⁸

Moreover, in the case of many youth who meet one of the SMHS Access Criteria, problematic behaviors are better understood as normative responses to their experiences of trauma. A diagnostic label may shift undue blame on the young person for their emotions and behaviors, rather than on the environmental and systemic structural factors that led to those symptoms. Youth from marginalized communities are particularly at risk. One analysis of ODD diagnoses, for example, observed that, because Black, Latinx and Indigenous youth face disproportionately higher levels of ACEs, “a significant proportion of ODD diagnoses therefore may incorrectly pathologize the trauma responses of these youth while drawing attention away from important social contexts.”⁹

A mental health diagnosis can remain in a young person’s school and/or medical records for years to come, potentially distorting how future teachers and therapists learn about and understand their story. A diagnosis can also limit a young person’s job prospects and prevent them from joining the military.

Below are two hypothetical situations in which a mental health diagnosis would risk undermining the youth’s treatment.

- A diagnosis could lead other professionals to make incorrect assumptions about the youth.

Tristan, 17 year old boy who recently was released from juvenile hall, has been engaging in challenging behaviors in school, including angry outbursts directed at his teacher. He is also resistant to directions from any school authority figure. He has revealed to his school therapist that he suffered repeated abuse by a staff member while at juvenile hall and that he struggles with intense anger resulting from those experiences.

In light of his behaviors, Tristan meets the diagnostic criteria for ODD. His therapist, however, is aware of the research suggesting that a diagnosis of ODD may negatively affect how his teachers and other school staff will perceive him for years to come. In the clinical judgement of his therapist, moreover, an ODD diagnosis is not necessary to the development of his treatment plan, which will include: 1) therapy to address the traumatic experiences he endured in juvenile hall; and 2) school-based Therapeutic Behavioral Services to help him build the skills he needs to manage his strong emotions and reactive behaviors.

- A diagnoses could cause the youth and/or family to refuse services.

15-year-old Adriana and her family have faced intermittent homelessness for many months. In part due to the stress of living without a stable residence, she struggles with sadness and severe withdrawal. She also has begun to engage in cutting behaviors. She meets the diagnostic criteria for depression, and, in light of her severe symptoms, SMHS are medically necessary.

⁸ Baglivio, MT, et. al. (2017), Racial/Ethnic Disproportionality in Psychiatric Diagnoses and Treatment in a Sample of Serious Juvenile Offenders, *Journal of Youth and Adolescence*, 46, 1424-1451.

⁹ Beltran, S. et. al. (2021), A Call to Revise the Diagnosis of Oppositional Defiant Disorder—Diagnoses Are for Helping, Not Harming, *Journal of the American Medical Association Psychiatry*, 78(11).

Adriana has been reluctant to engage in treatment because her family's cultural influences historically have stigmatized individuals with mental health challenges. Her therapist predicts that, if he tells Adriana he has diagnosed her with depression, she and/or her parents are likely to decide she must withdraw from treatment. The therapist chooses to proceed with therapy that addresses her individual mental health symptoms and their underlying causes, without initially issuing a diagnosis. The therapist plans, over time, to educate Adriana and her parents about the value of acknowledging and addressing mental health conditions.

Conclusion

CalAIM has created a groundbreaking opportunity for mental health providers to look beyond the presence or absence of a youth's diagnosis, and to consider instead the full range of factors that shape a youth's current and future mental health. We urge DHCS to take full advantage of this new reform by empowering mental health staff to provide all medically necessary SMHS to youth who meet one of the SMHS Access Criteria, even in cases in which a mental health diagnosis is not warranted or would be detrimental to the current and future well-being of the youth.