The care is missing because the code is missing

Few of the billing codes used across American health care are for behavioral health[1,2] — and most are written by a private trade association, not a public body.[3] Missing codes leave constituents stranded in all 435 congressional districts and every state.

THE SOLUTION:

A federal Behavioral Health Coding Council.

Permanent. Independent. With mandatory seats for people with lived experience and the behavioral health professionals who deliver the care — neither of which reliably reaches the table today.

Nothing about behavioral health billing without us.

HOW A MISSING CODE REMOVES CARE

Every medical service must have a code before it can be billed. Most are CPT billing codes, owned by the American Medical Association; the rest are HCPCS codes administered by CMS.[4] No code, no payment. No payment, no program. When a code is missing, the service moves outside insurance: families pay cash or go without, and clinicians absorb the loss until they stop providing the service.

0	8.9x	288
of 21 seats on the panel that writes CPT are held by patients or families[3]	more likely a psychiatrist visit is out of network than another specialist's[5]	codes added for 2026 — 46 for one leg surgery, none for a new behavioral health service[2]

CASE IN POINT ▶ DIALECTICAL BEHAVIOR THERAPY

DBT is a leading evidence-based treatment for borderline personality disorder and for people who struggle with suicidality, self-harm, and emotion dysregulation. Eighteen controlled trials show it reduces self-directed violence and use of psychiatric crisis services.[6] Some show suicide attempts cut by about half.[6] Its four components are delivered together — remove one and it is a different treatment.[7]

Weekly individual therapy	PAYABLE
Group skills training	INCOMPLETE CODE
Phone coaching between sessions	NO REIMBURSABLE CODE
Therapist consultation team	NO REIMBURSABLE CODE

When patients, families, and advocacy groups petitioned CMS in 2025 for a comprehensive DBT code, the application was not accepted: **wrong door, go to the AMA**.

DBT is one example of missing codes. **EMDR intensives and extended therapy sessions face the same barrier** — the codes that paid for psychotherapy beyond sixty minutes were deleted January 1, 2023, and never replaced.[8]

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Who writes the codes?

A PRIVATE BODY, A PUBLIC CONSEQUENCE

The American Medical Association owns CPT and licenses it back to the federal government and to every payer and provider. It represents roughly 26 percent of practicing physicians yet controls the language all of them must bill in.[9] CPT royalties brought it about $285 million in 2023 — a significant portion of its revenue.[10]

The panel that decides CPT has 21 seats: twelve for physician specialty societies, two rotating among thirteen non-physician organizations — licensed professional counselors are not eligible even to rotate. No seat belongs to a patient or family member.[3]

> "The government has endorsed a coding monopoly for the AMA."
>
> Sen. Bill Cassidy, M.D., Chairman, Senate Help Committee | Letter to the AMA | October 6, 2025[11]

WHAT THE COUNCIL SHOULD DO

1. Seat, by statute, people with lived experience and the behavioral health professionals who deliver the care.
2. Consultation authority over behavioral health coding decisions, with authority to direct CMS on HCPCS codes where CPT does not cover the service.
3. Recommend new and revised codes for evidence-based services, starting with DBT.
4. Require a formal, time-bound response from CMS and HHS to each recommendation.
5. Track unresolved gaps and the access consequences of coding additions, deletions, and changes.

WHY THIS IS THE RIGHT INSTRUMENT

Parity law already requires behavioral health to be covered no more restrictively than physical health, but it cannot deliver when the code to bill the service does not exist. **A council that fixes the codes makes the laws already on the books enforceable** — without setting rates, displacing CPT, or creating a new benefit. The cost is one advisory body, against what the country pays for the absence of one.

WHAT WE ARE ASKING FROM YOUR OFFICE

1. Sponsor or support legislation establishing a federal Behavioral Health Coding Council.
2. Ask CMS and the AMA, on the record, whose job it is to seek a billing code. Is it the patient's responsibility?

We are the Missing Codes Coalition — patients, families, and clinicians who have spent years inside this system. We have testified, surveyed providers, and petitioned CMS for a single billing code.

SOURCES

1. AMA, Behavioral Health Coding Guide, updated Mar. 7, 2025.
2. AMA, "AMA Releases CPT 2026 Code Set," Sept. 11, 2025.
3. AMA, "Purpose of the CPT Coding System and the CPT Editorial Panel," 2025.
4. AMA, CPT basics; CMS, HCPCS Level II.
5. T.L. Mark et al., RTI International, 2024.
6. DeCou, Comtois, and Landes, Behavior Therapy 50, no. 1 (2019): 60–72. Linehan et al., Arch. Gen. Psychiatry, 2006. Storebø et al., Cochrane, 2020.
7. DBT-Linehan Board of Certification.
8. AMA, CPT 2023 code set — 99354 and 99355 deleted eff. Jan. 1, 2023.
9. Sen. Bill Cassidy, M.D., Senate HELP Committee, letter to the AMA, Oct. 6, 2025.
10. AMA, 2023 Annual Report — royalties approx. $285M, about 61% of revenue.
11. Cassidy letter, Oct. 6, 2025 (see 9). Full citations at themissingcodes.com.

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