

SUMMARY OF CHANGES TO THE PROTECTING JESSICA GRUBB'S LEGACY ACT

The primary changes made to the Protecting Jessica Grubb's Legacy Act would allow patients to opt in and share their addiction medical records because current law makes it "difficult or impossible" to share addiction medical records in a variety of coordinated care settings including Health Information Exchanges and Medicare Accountable Care Organizations. The Legacy Act will make it easier to share addiction records for the purposes of treatment, payment and healthcare operations, while allowing patients to remain in control, as well as providing new protections not afforded under 42 CFR Part 2, which was passed into law in the 1970s, well before HIPAA and electronic medical records.

This is an ideal compromise that alleviates the roadblocks to care coordination, while providing strong protections, and more importantly providing those suffering with substance use disorder, more comfortable in knowing they can share medical records in a protected manner and enforced with real penalties to prevent misuse of sensitive medical information.

CHANGES:

INITIAL CONSENT – The modified language would require affirmative, written consent from each patient to opt-in before their information may be shared. In response to additional requests from stakeholders, the following changes were also included:

- An education component to ensure patients understood what they were consenting to before making a final determination.
- An expansion of the scope to align it with all HIPPA regulations.
- An opt-out clause to allow patients an opportunity to rescind this consent if they changed their minds in the future.

ANTI-DISCRIMINATION – To further protect patients, existing patient protections are enhanced to prevent discriminatory behavior towards patients suffering from substance use disorder in relation to:

- Access to treatment
- Termination of employment
- Receipt of worker's compensation
- Rental housing
- Social services and benefits provided by federal, state or local governments

COLLABORATIVE RULEMAKING – To ensure all stakeholders are included in implementation, the Legacy Act directs the Secretary of Health and Human Services to consult with appropriate legal, clinical, privacy, and civil rights experts when updating the Code of Federal Regulations to implement the provisions contained in the bill.

From the Office of
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